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**“A social constructivist narrative exploration of women with an intellectual disability and nurses in English secure services”**

**Angela Ruth Ridley**

**A thesis submitted in partial fulfilment  
of the requirements of the  
University of Northumbria at Newcastle  
for the degree of  
Professional Doctorate**

**Research undertaken in the Faculty of Health and  
Life Sciences, Department of Nursing, Midwifery and  
Health**

**September 2020**

## **Declaration**

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I also confirm that this work fully acknowledges opinions, ideas and contributions from the work of others.

Any ethical clearance for the research presented in this thesis has been approved. Approval has been sought and granted by Northumbria University Faculty of Health and Life Science Research Ethics Committee and the Health Research Authority/Integrated Research Application System project ID number 236235 on 5.10.2018.

**I declare that the word count of this thesis is 71273**

Name: Angela Ruth Ridley

Signature:

## Abstract

Little research has been undertaken with women with an Intellectual Disability (ID) who have experienced secure services, and there is a similar picture with the registered nurses (RNs) who support them. Secure services (SS) support people with an ID who may have experienced the criminal justice system (CJS), need security and/or have a health need.

The overall aim of this study was to explore the experiences of women with an ID (the women) within secure services and how registered nurses (the nurses) support those women. The principal research question in the research was 'What are the experiences of women with an intellectual disability within secure services and how do the nurses support them?'

The objectives were to:

1. Develop innovative qualitative methodological approaches in exploratory research with female patients who have an ID and are in secure services.
2. Explore the treatment of women with ID by secure services based on the lived experiences as told by the women and the nurses.
3. Discover, through the stories of women and the nurses, the nature and provision of significant support provided to or accessed by women with an ID in secure settings.
4. Find out what the nurses' perspectives are about their preparation and practice for working in female ID secure services.
5. To make recommendations for the future with suggestions and guidance for women with an ID in secure services, their families, researchers, staff working in women's secure ID services, educators, and service provision.

There were two research sites in the study, both located in the North East of England. Women with an ID who have previously accessed or are currently

accessing secure services; registered nurses (male or female) who have supported the women in the past or are currently supporting the women in secure services, were eligible to take part. Participants were recruited from both research sites, this included twelve nurses who were all female and eight women ( $n=20$ ).

This research adopted a narrative approach using semi-structured interviews carried out by the researcher. The study was designed to include participants who required the presence of staff, which may have otherwise thwarted participation in some research studies. The constant presence of staff may have conflicted with the confidential relationship between researchers and participants. Moreover, gathering data from the women with staff present, enabled the researcher to conduct interviews and utilise a blended approach of interview styles. An approach that created a unique and innovative methodological approach to conducting semi structured interviews with participants who have an ID, and staff are required to be present.

The corpus of raw data gathered from the semi-structured interviews was analysed and generated into codes, candidate themes, then themes as adapted from Braun and Clarke's (2006) model of Thematic Analysis. This was inductive in nature and meant a creative, organic approach to coding and theme development could be taken, likened to Big Q data analysis. The themes were not waiting to be found (as in small q data analysis), the researcher was able to create the themes from generating the data and retain the narrative in its purist form. The analysed data formed overarching themes from all the participants, which in some instances were shared themes from the women and the nurses.

The themes are presented in this thesis chronologically; the past, present and future. The past shows how the participants have had a complex journey with services over a prolonged period of time, which in turn has shaped their identity. The present shows the current experience, relationships, and gender to be existing issues in the

lives of the participants. The future highlights the long-term views and aspirations held by the participants.

The recommendations in this research are aimed at women with an ID and their families, future researchers in the field of ID, staff working in women's secure ID services, educators, and future service provision. This research has produced a unique contribution to the body of knowledge in the field of women with an ID and the nurses who support them. By providing an innovative methodological approach to conducting research with participants who have an ID and may otherwise be excluded from participating in research. This research recommends a blended approach to conducting semi-structured interviews and a new way to hear from women with an ID, which is best described in the acronym INTREPID (interviewing using a narrative approach with a third-party present, for conducting research ethically with participants who have intellectual disabilities).

## **Acknowledgements**

**I would like to offer my sincerest thanks to the women and the nurses in this research study. Who were open, honest and trusted me with their personal narratives, it was an honour and privilege to hear about your experiences. Your stories were moving and inspiring and this thesis is presented to tell others your story. Thank you all so much, you were amazing.**

**I wish to offer my sincere thanks to my family, my friends, my critical friends, and my supervisor Dr McClelland. Without all of you, this would not have been possible.**

**To Hannah and Charlotte, thank you for your constant support, patience and believing in me over the past five years. Thank you for making me proud every day and for being such wonderful daughters. And finally, to my mother Patricia.**

**This work is dedicated to you all.**



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## Chapter 1: Introduction

### 1.1 Introducing the research subject

Historically, people with intellectual disabilities (ID) have been treated differently from the general population, often with negative outcomes. Women with an ID are a small distinctive population, as opposed to the significant numbers of their male counterparts. There are women with an ID who have required Secure Services (SS) for reasons of health, behaviour, or as a legal requirement. Generally, the provision of such services has been patchy and sporadic. Because of the uniqueness of this population, women with an ID in SS are often overlooked in research, hence the importance of this thesis. This study explores the experiences of women with ID (the women) in SS and of the registered nurses (the nurses) who support them.

The current state of research about women with ID and the nurses who support them in SS is scarce, since the majority of researchers have tended to favour studies with male populations in SS (Lindsay *et al.*, 2004). Some studies have focused on carers of people with ID, and few global studies have researched nurses' perceptions of ID nursing. Two studies explored the same topic; views of service users on sexuality (Healy *et al.*, 2009), then carers and family's views on sexuality (Evans *et al.*, 2009), both were independent studies yet are known in the literature as Part 1 and Part 2. No studies have been conducted exploring both the experiences of the women with an ID in SS and the nurses who support them in one study. This research study aims to address that gap in research studies.

Women with an ID are supported in SS by a multi-disciplinary team (MDT), with the central role usually being taken by a registered learning disability nurse (RNLD), and sometimes can include Registered Nurses Mental Health (RNMH). The roles of the registered nurses can include acting as a named nurse, keyworker or sometimes the responsible clinician (RC). This is crucial because the role of the Registered Nurse is essential to the care and support a woman with an ID receives whilst in SS. This is

important to this study because this research will explore the experiences of care management and treatment of women with an ID, as well as the practice and preparation of RNs to work with this group of patients. This area of examination will be in relation to their background, training, and perceptions. The perceptions, practice, assumptions, and experiences of the RNs will be equally important to this research as the experiences of the women with an ID.

There are strategies in place to protect the rights of anyone who has experienced the Criminal Justice System (CJS). The Human Rights Act (1998) and the Police and Criminal Evidence Act (PACE, 1984) are examples of primary legislation in place to protect the public, practitioners, witnesses, victims, and defendants from arbitrary decisions. There is an abundance of literature and empirical studies about men with an ID in the CJS (Hayes, 2007), yet less is understood about women with an ID in the same situation, which could be attributed to the higher numbers of men with an ID in SS. Making provision of services, funding, and research a higher priority for men with an ID than for far less numbers of women with an ID in SS. That said, numerous studies highlight the need for further in-depth research into supporting women with an ID in SS (Bradley, 2009; Corston, 2007; Lindsay *et al.*, 2004; Fish, 2012). There is clearly an unmet need in this population.

This research study aims to add to the current body of knowledge by providing new understandings in this specialised area. This study will assist clinicians, educators, service providers and researchers to further the subject matter in a way that can enhance what is known about the lives of women with an ID in Secure Services.

The use of acronyms is common in research and nursing, and this thesis will refer to an established set of global terms and abbreviations by using acronyms. This is to demonstrate that the researcher is conversant with the global terms, abbreviations, and current terminology. This research study will adopt the global term of intellectual disability when referring to people with learning/intellectual disability. The current use of the term secure services (SS) will also be applied, however forensic may be

referred to if this was used by the original author(s) in a piece of work. Acronyms applied in this thesis can be found in table 14 - appendices section.

## 1.2 Aims and objectives of this research study.

The principal question in the research study is 'What are the experiences of women with an intellectual disability within secure services and how do the nurses support them?'

To answer the research question there were five objectives in the research study, which were;

1. To develop innovative qualitative methodological approaches in exploratory research with female patients who have an ID and are in secure services.
2. To explore the treatment of women with ID by secure services based on the lived experiences as told by the women and the nurses.
3. To discover, through the stories of women and the nurses, the nature and provision of significant support provided to or accessed by women with an ID in secure settings.
4. To find out what the nurses' perspectives are about their preparation and practice for working in female ID secure services.
5. To make recommendations for the future with suggestions and guidance for women with an ID in secure services, their families, researchers, staff working in women's secure ID services, educators, and service provision.



### 1.3 Participants and research sites

This research study recruited participants who are women with an ID and have experienced or currently are experiencing secure female ID services. Additionally, participants were registered learning disability nurses or registered mental health nurses who have worked or are currently working in female ID SS. This means that participants have experienced secure female ID services and are best placed to be able to answer the principal research question, which is 'What are the experiences of women with ID in SS and how do nurses support them?'

There are two research sites in the research study, Site A and Site B, both of which are in the northern region of England. Both sites were selected because they currently provide secure female ID services or have done in the past fifteen years. Both sites employ RNs (learning disability and mental health). Essentially, the reason the research sites were selected was because of the service provision and because they employed RNs, which meant they were the most likely sites to identify potential participants. Both research sites provided low and medium secure services for women with an ID, not an enhanced women's medium secure service.

Specifically, this research study addresses the issues of treatment experienced by women with an ID of SS, exploring how the women talk about their experiences. The study also focuses on how the nurses view the way they support the women, and how they are prepared and trained to do the job, thus examining the levels of support provided for the women and finding out where their supportive relationships are.

Participants in this research include women with an ID from SS and Registered Nurses who were female or male. Hence, men with an ID and other healthcare professionals will not be included in the study. Boundaries of the research sites have been selected for their extensive service provision, as they are amongst the largest

providers of in-patient ID services and located within the northern region. This research study will not include the entire national SS for women with an ID, nor every RN who has worked in women's secure ID services.

## 1.4 Timeline of policy and legislation

Historically people with an ID were labelled as 'lunatics' and 'idiots,' the Lunacy Act, (1845) and the Idiots Act (1886) categorised ID and MH as one and the same. The Asylum of Idiots charity created four regional asylums across England in the 1850-1860, the purpose of which was to house 'idiots' in large-scale facilities on a voluntary basis. A later version of the Lunacy Act (1890) maintained no distinction between having an ID or MH and sustained their incarceration. Later developments included the introduction of colonies in 1902 and the establishment of Eugenics Education in 1907. The Mental Deficiency Act (1913) introduced idiot, imbecile, feeble minded and moral imbeciles as accepted terms, and continued to force those with an ID to live in asylums. This provided the legal justification to institutionalise poverty-stricken women with illegitimate children. The use of lunatic and idiot were deemed harsh, and hence mental retardation was introduced in 1961 and included in the Diagnostic Statistical Manual.

Between 1939 and 1941 people with an ID were murdered under the euthanasia programme by Nazi Germany. This practice continued secretly until 1945, killing an estimated 200,000 people ([www.langdondownmuseum.org.uk](http://www.langdondownmuseum.org.uk)). Professor Hans Asperger persuaded Nazi control that those with a certain condition (now known as Asperger syndrome) would be useful to the government due to their distinct abilities, thus sparing many from death. Asperger first identified autistic psychopathy (autism – self and psychopathy - personality) in 1944 ([www.autismuk.com](http://www.autismuk.com)).

In 1948 The Universal Declaration of Human Rights stated everyone had the right to life, liberty and security of person. The same year the NHS was formed and took over responsibility of asylums, renaming them as institutions. The National Council

for Civil Liberties reported that everyone should be free from harm. In 1958, The Brooklands Experiment led by Professor Tizard found that children developed further in small community living as opposed to institutions. This revolutionary research began the debate about community living and closure of institutions.

The pervasive societal views held during the late nineteenth and early twentieth century towards people with an ID were perceived as burdensome and responsible for the 'social ills' of the time. The feeble minded were associated with criminality, prostitution and alcoholism (Tredgold, 1909 pp.97-104), and a belief that reproduction would circulate such ills amongst the rest of society. There was growing impetus to sterilise women with an ID, a practice that continued for many years and still does in some countries. However, the implementation of the European Convention on Human Rights (1950) gave human and civil rights to every person. This included giving choices to women with an ID around contraception and family planning. Undoubtedly, progress has been made over the decades for people with an ID. The position for women with an ID in secure services has been influenced by policy (DoH, 2002) and the high cost of service provision.

The Mental Health Act 1959 (MHA, 1959) repealed the Mental Deficiency Act (1913) and Lunacy Act (1890), thus removing the terms that were formerly referred to. Removal of the term 'moral defectives' meant that women could no longer be institutionalised for having a child out of wedlock (legislation.gov.uk). This statute provided distinction for the first time between ID and mental illness, as defined as mental disorder. The Mental Health Act progressed the voluntary nature of a patient's status in an institution and promoted care in the community.

In 1971, The White Paper '*Better Services for the Mentally Handicapped*' was launched in the UK. The Paper set out the aim to end custodial practices and plans to reduce hospital places by 50%, this would be achieved through increased local authority provision of residential and day care services (HMSO, 1971). Additionally, recommending that staff were re-trained to adopt a Normalisation philosophy of care,

defined as 'culturally normative as possible' (Wolfensberger, 1972). In 1979 The Jay Report re-affirmed the need for a shift in provision of care to local authorities, and crucially that services were based on the principles of normalisation (Jay, 1979). This was followed by a review of statutory provision and subsequent legislative developments. The MHA 1959 was repealed, and The MHA 1983 was enacted, providing the legal framework for assessment, treatment and detention of vulnerable people with a mental disorder (legislation.gov.uk). In essence this meant people with ID could be supported in the community, and there was legal justification to detain those who were at risk and required admission to secure services.

Recommendations for changes in secure settings for offenders/alleged offenders, was set out in The Reed Report (1992). The report recommended that high quality care should be provided according to need, additionally that offenders were not caught up in the CJS unnecessarily. More specifically, services should be near to the persons home and if possible, in the community. The climate at the time seemed to support the development of individual rights and freedoms, with emphasis on the emerging growth in cases involving challenging arbitrary decisions as well as protecting human rights and fundamental freedoms. Thus, the Human Rights Act 1998 (HRA) (legislation.gov.uk) was given royal assent in October 1998 and came into force in 2000. This two-year lapse was to allow time for the judiciary to address the training needs required, since this new point of primary legislation would have an extensive impact on future jurisprudence in the UK. The HRA has been condemned as a departure in constitutional politics by derogation of power from law makers to the courts, thus undermining parliamentary sovereignty (Campbell *et al.*, 2011). However, The British Institute of Human Rights has since celebrated the HRA 1998 as a herald in the judicial crown ([www.bihl.org.uk](http://www.bihl.org.uk)).

The Magistrates court presides over approximately 90% of criminal trials in England and Wales, thus overseen by individuals who are unpaid and frequently have limited legal qualifications (Brooks, 2017, p.13). The Joint Committee on Human Rights (2008) found that people with an ID are more likely to experience infringements of their human rights, and Article 6 '*The right to a fair trial*' is one of the rights afforded

to everyone. Yet a fair trial includes the presence of an appropriate adult (AA), even though many are unsure what the role of an AA is, resulting in variable practices where there is no AA service (Farrugia and Gabbert, 2019). Importantly, there were no challenges of the right to a fair trial under Article 6 found by women with an ID who have been convicted by the CJS. Moreover, a nurse or other healthcare professional could not instigate a challenge to this process on behalf of a woman with an ID. It seems likely that a woman with an ID who has been convicted would be unable to negotiate the CJS, would not know what an AA is and the nurse who is ultimately responsible for her would be unable to lodge an appeal in any event.

Challenges to detainment within the meaning of the MHA were made in The Bournemouth (R v Bournemouth, 1998) case, and the subsequent many years of legal challenge which followed in the domestic courts in 1998. Ultimately the result was a ground-breaking decision by the European Court of Human Rights, with a declaration of incompatibility of UK domestic law with the rights and freedoms of vulnerable people (HL v The United Kingdom 2004). As a consequence, the Deprivation of Liberty Safeguards (DoLS) were implemented through an amendment to the Mental Capacity Act 2005 ([legislation.gov.uk](http://legislation.gov.uk)). This gives legal justification to deprive a person of their liberty if they lack capacity. In practice this means a person has protection from arbitrary decisions, whilst not being detained within the remit of the Mental Health Act, which provides protection in itself. The implementation of the DoLS was a breakthrough in statutory provision, which in essence means that people who do not have capacity do not need to be detained under the Mental Health Act but have protection in any event. The Mental Capacity Act 2005/DoLS provides the legal framework to act and make decisions on behalf of a person who lacks capacity ([legislation.gov.uk](http://legislation.gov.uk)). The act is designed to protect vulnerable people from professionals making subjective decisions on their behalf, as well as providing legal recourse for those who do not need to be detained within the remit of the Mental Health Act. This is precisely the travesty in the decision made by the professionals when managing HL in The Bournemouth case, though there was a second travesty in the seven years it took for the ruling to be made. During that time there were almost certainly more similar cases to HL that were unchallenged,

resulting in a significant amount of people with an ID being detained when they need not have been.

Choice and inclusion became a government agenda item, and the objective was to enable people with an ID to live a full and valued life. The report *Valuing People: A New Strategy for Learning Disability for the 21st Century* (gov.uk 2001) outlined the governmental approach. Funding to support the transition from hospitals to community, advocacy forums and national targets associated with quality in ID services were prioritised. This agenda aimed to put an end to the last of the long stay hospitals. *Valuing People Now* (2009) provided an update on the progress of *Valuing People*. This report provided some positive case examples as well as highlighting the issues. The report highlighted the ongoing issues and was a further iteration of the point that more work was needed in providing quality care and support for the most vulnerable in society.

*Transforming Care: A national response to Winterbourne View Hospital* (Department of Health Review and Response, 2012) was implemented to reduce the number of in-patient hospital beds. This was followed by *Building the Right Support* (NHS England, 2015), which aimed to address the scarce provision of community services. The NHS, CCGs, social care and independent provider organisations implemented a Fast-Track Transformation plan before the Winterbourne View scandal but admitted that not enough progress had been achieved to reduce the number of in-patient beds (www.darlington.gov.uk, 2016). However, some authors have criticised the implementation of *Transforming Care* (Bubb, 2014) as a means to which patients will be admitted to private sector hospital beds, which is where the problem started in the first place (Taylor *et al.*, 2017). *Transforming Care* is reported to have failed people with Autism (Marshall-Tate *et al.*, 2017). It seems that the response to the scandal may have been presumptuous, ill-prepared and the cause of more problems.

## 1.5 Intellectual disabilities

Learning disability is an umbrella term used to describe individuals who have impaired intelligence and social functioning which occurred during childhood (Barr and Gates, 2019), along with a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence), which results in a reduced ability to cope independently (impaired social functioning) (Watson *et al.*, 2012). The impairment can have a lasting effect and begins before adulthood (Webb and Simon, 2012). It is widely accepted that people with a learning disability may need assistance with everyday living, particularly those with moderate or profound disabilities. The use of the global definition, intellectual disability (ID), includes learning disability and learning difficulty and is now becoming more widely used (Cluey, 2018). The American Association on Intellectual and Developmental Disabilities (AAIDD) moved from the term mental retardation to intellectual disability (Schalock *et al.*, 2007). This research included people with a learning disability and/or learning difficulty, although learning disability is the accepted term used in the UK (Gates and Mafuba, 2016). Thus, for completeness and universal application, the global term intellectual disability (ID) will be used throughout this thesis.

The presence of an ID can be determined using a range of diagnostic tools. In children's services, the term global developmental delay is referred to, and this serves to acknowledge the presence of an impairment before a diagnosis can be made (Moeschler and Shevell, 2014). Traditional diagnosis included scoring on a standard intelligence quotient (IQ) test (Stanford-Binet, 1905 cited in Glutting, 1989). Contemporary diagnostic tools involve more qualitative approaches focussing on daily living skills, as opposed to an IQ range (American Psychiatric Association, 2013). Similarly, the Diagnostic Statistical Manual V defines ID as a neurodevelopmental disorder, with deficits in adaptive and intellectual functioning and an onset which must have taken place during the first two decades of life (DSM 5), thus removing the IQ threshold. The International Classification of Diseases–11<sup>th</sup> Edition's (ICD-11) balances IQ measurement and skill ability (WHO, 2015), thus

considering intellectual functioning as well as the ability to perform tasks, which means there is an objective approach with a focus on positive abilities that may have previously been unnoticed. The problem with introducing an objective element to assessment and diagnoses is that the opinion of a professional is fundamental and may introduce a bias. There is a contradiction in measuring IQ in those with Autism Spectrum Disorder (ASD). Often the term 'high functioning' is used to describe those with ASD who do not have an ID, and there is fresh impetus to have the term high functioning removed from research and practice (Alvares *et al.*, 2020). This seems a logical way forward since the term high functioning is stigmatising and sets levels amongst those that are/are not high functioning.

Identity for people with an ID has been an issue for decades. The concept of social role valorisation (Wolfensberger, 1983) emerged from Normalisation principles first described in 1972 (Wolfensberger, 1972). Social role valorisation acknowledges the societal views towards vulnerable others, how they are viewed as lesser members of society. And proposed to create, support and defend valued social roles, for those who were at risk of being de-valued, as well as supporting community paradigms. This approach was accepted in the Five Service accomplishments (O'Brien and Tyne, 1981) and became embedded into practice. Although, research indicates that those with an ID did not view having an ID as part of their identity, were unaware of having an ID or they felt that the diagnosis did not apply to them (Beart *et al.*, 2005). The reasons were cited as a desire to avoid being part of a stigmatised group, or denial as an avoidance technique. The issue of identity was updated in 2019 and three points were highlighted. Firstly, the majority of people with ID are aware of the label of being different, but, secondly, others rejected the label of ID and sought alternative labels. Finally, it was found that most people with an ID accepted that they are viewed by others negatively, which prompted feelings of shame, anger and powerlessness (Logeswaran *et al.*, 2019). However, some reported positive outcomes once they had accepted the label, for example accessing advocacy services.

Whilst the difficulty in establishing the presence of an ID is recognised, the presence of an ID in the prison population was found to be higher than previously suggested



(Hayes *et al.*, 2007). In a random sample from a large prison population ( $n=140$ ) it was found that 7.1% participants achieved an IQ score of below 70 and 23.6% were in the borderline category with an IQ of 70-79. This illustrates the presence of an ID has gone undetected in that the person may have needed SS as opposed to prison, which has implications for the treatment of prisoners as well as post-release support.

## 1.6 Prevalence of intellectual disabilities

It is suggested that there are no definitive figures of the prevalence of an ID. One possibility for this is the lack of engagement with services and a resulting low number in diagnosis. However, estimates in 2011 demonstrated that there were over one and a half million people in Britain who have a learning disability and the number was predicted to increase in ten years by 14% (Emerson and Hatton, 2011). This included 905,000 adults aged 18+ (530,000 men and 375,000 women), which means for every woman with an ID there are 1.5 men.

In 2015 it was reported that there were 1,087,100 people with ID in England, including 930,400 adults; equating to 2.16% of the adult population (Public Health England, 2015). In the same report it was found that the highest occurrence of ID was in Cumbria and the North East of England. One reason for this could be the extensive ID services provided by Cumbria, Northumberland, Tyne Wear Foundation Trust, with an annual budget of £380 million, including regional and national specialist services and seventy sites stretching from North East coastal towns to the North West coast of England ([cntwft.nhs.uk](http://cntwft.nhs.uk)). Prevalence of ID in 2016 stated that 3-4/1000 of the general population would have a severe ID, and 25-30/1000 will have a mild ID (Hatton *et al.*, 2016). The figure remains at 1.5 million and still set to rise ([www.nhs.uk](http://www.nhs.uk), 2018). Estimated figures have also suggested the largest proportion is those with a mild learning disability, who make up around 2.5% of the whole population (Cooke *et al.*, 2003).

## 1.7 Secure services

National Health Service (NHS) England have recently adopted the term 'secure' as opposed to forensic, when referring to SS. The change is a reflection that SS may not always indicate contact between the patient and the justice system, even though a secure service is required. In line with contemporary terminology the term secure will be used in this research. SS for a woman with an ID is the interface between the CJS and healthcare, and this is important as many women with an ID encountering the CJS have multiple and complex diagnoses that include mental health issues, and they may have a history of victimisation/abuse, exploitation and/or drug and alcohol abuse (Lindsay *et al.*, 2006; Beber, 2012; Lindsay *et al.*, 2012). The terms used to describe people with an ID who access services can be used interchangeably. This can alter depending upon the type of service being provided, for example patient, service user or client. A woman with an ID who has accessed SS within the NHS is referred to as a patient. The term 'the women' will be used throughout this research to describe women with an ID who have experienced a SS.

The number of women with an ID in secure settings is significantly lower than the numbers of men with an ID in SS. Women with an ID make up 25% of the secure population (Noods and Collins, 2003), making this a small and distinctive population. Due to relatively low numbers of women to men in secure ID services, provision of services and funding focuses on the needs of male patients (Lindsay *et al.*, 2004). Similarly, research that has been undertaken has primarily favoured the area of men with an ID in SS (Hellenbach *et al.*, 2014). Since there has been little research conducted in the area of women with ID in SS, it means the evidence base is scarce, thus the needs of this vulnerable population are somewhat overlooked. Key professionals who support women with ID (the women) in SS are registered nurses (the nurses). This research study brings together both the women and the nurses in a unique way. Using a narrative approach this research explores the experiences of the women and how the nurses support them. Through semi-structured interviews the women and the nurses were able to talk about their own experiences.

## 1.8 Prevalence of women with an intellectual disability in secure services

There is little known about this minority population. Coid *et al.*, (2000) stated that if the women require secure settings, they might automatically be referred to high security. Further, Crossland *et al.*, (2017) noted that the needs of the women in SS are different and distinct, nevertheless the evidence base in relation to this population is limited.

Nationally, there are between 8 and 10% of patients in medium secure settings who are women (Dent, 2006), later reported to be 1,625 beds (Harty *et al.*, 2012). This figure is four times as many as in 1995 (Hassell and Bartlett, 2001). Whilst this is a minority population, women in secure health settings lose their liberty four times longer than women in prison and for longer than men in secure health (Aitken and Logan, 2004). This is illustrative of a rise in numbers and a disproportionate outcome for women as opposed to men, affirming the need for more research into the distinct population of women in SS. Furthermore, despite women making up only 6% of the prison population (Sarker and di Lustro, 2011), they represent 25% of the secure (forensic) health population (Noods and Collins, 2003).

Prevalence of those with an ID receiving in-patient services is a much-debated issue, and the only certainty is the uncertainty in numbers (Corston, 2007). The Health and Social Care Information Centre (HSCIC, 2015) aimed to establish the figures and conducted a census to audit learning disability services, on behalf of the NHS, DoH, CQC, PHE and NHS England. Furthermore, this momentum was a direct response to implementing Transforming Care: A National response to Winterbourne View Hospital (Department of Health Review and Response, 2012). There are three high security hospitals in England, which is far less than medium and low secure. The audit (HSCIC, 2015) found that there were 3,000 patients receiving in-patient care at the time of the census, showing that ethnicity was comparable to the population in England, while age and gender differed. The data indicated that out of the total

number of patients (3000), there were 810 (53%) patients in low secure, 525 (17%) in medium secure and 70 (2%) were in high secure units. Security level was identified as an important issue since this was the prevailing factor in deciding where a patient was placed. 38% (280) of females were more likely than males (20%/445) to be placed in a mixed gender ward (HSCIC, 2015). 69% of females (515) experienced at least one incident of self-harm, accidents, physical assault, restraint or seclusion, compared to 51% of males (1,155). Females were more likely than males to experience both an adverse experience and a restrictive measure (290 females (39%) with 485 men (22%)). Males were marginally more likely to experience just a restrictive measure, whilst females were marginally more likely to experience just an adverse experience. This data is relevant to this research study since the women were placed (or had previously been placed) in medium or low secure settings/mixed gender wards, and additionally may be part of the discharge numbers from implementing Transforming Care. The incidence of women with an ID in SS is even less predictable. Crocombe *et al.*, (2006) conducted a study of the female population ( $n=51$ ) in Broadmoor (one of the three high secure hospitals in England), and found that over 10% of the women met the criteria in ICD-10 for an ASD. They concluded that the characteristics and over representation required further investigation, which is significant to this research since the inclusion criteria is having an ID but not ASD. Literature has shown that there is gender specificity and a degree of 'camouflaging' in relation to diagnosing ASD in women (Green *et al.*, 2019).

Alexander *et al.*, (2010) studied admissions to hospital for offenders with ID and found women were in the minority (21%) and are more likely to have a diagnosis of personality disorder than male peers. Beber (2012) suggested these findings show that the most troubled and complex women are being admitted to forensic settings.

Harty *et al.*, (2012) conducted a mapping exercise as part of a pathway study of women in SS in England and Wales, exploring the extent and range of secure service provision. It was identified from the study there were 589 medium secure beds, 46 enhanced medium secure beds and 990 low secure beds for women

nationally. The majority (309/52%) were in the NHS, with under half (280/48%) in the independent sector. However, the provision of low secure beds had a reverse trend: (745/75%) in the independent sector and 254 (25%) in the NHS. The cost to provide one NHS inpatient bed in SS is £300,000 per year, as opposed to £535 per week for residential care provided by a private provider, equating to just under £28,000 per year (NICE, 2014). Consequently, women are a much smaller population, and such expensive services are disproportionately provided.

The need for non-generic services specialist to women with ID secure settings is not a new problem. However, women's services seem to have been left behind in research, policy and practice. At this important time, on the cusp of Transforming Care, it is essential to discover what women with an ID need, and this research study aims to explore the experiences of those women.

An audit was undertaken in a medium secure private hospital in the UK into the women's ID pathway (2009-2010). Of 21 admissions, they found 60% were admitted from court-imposed sanctions under the remit of the MHA. 91% were Caucasian with an IQ of 53-75 and 26% had children. 91% of these women were Caucasian with IQ's ranging from 53 – 75, 87% were not in a long-term relationship, and 27% had children. 65% had past forensic histories including assaults and 21% displayed challenging behaviours that had not reached the court's attention (Beber, 2012). Further, those who were mothers had their children removed, which demonstrates the psychiatric, intellectual, parental and relationship burden placed on the women in secure settings.

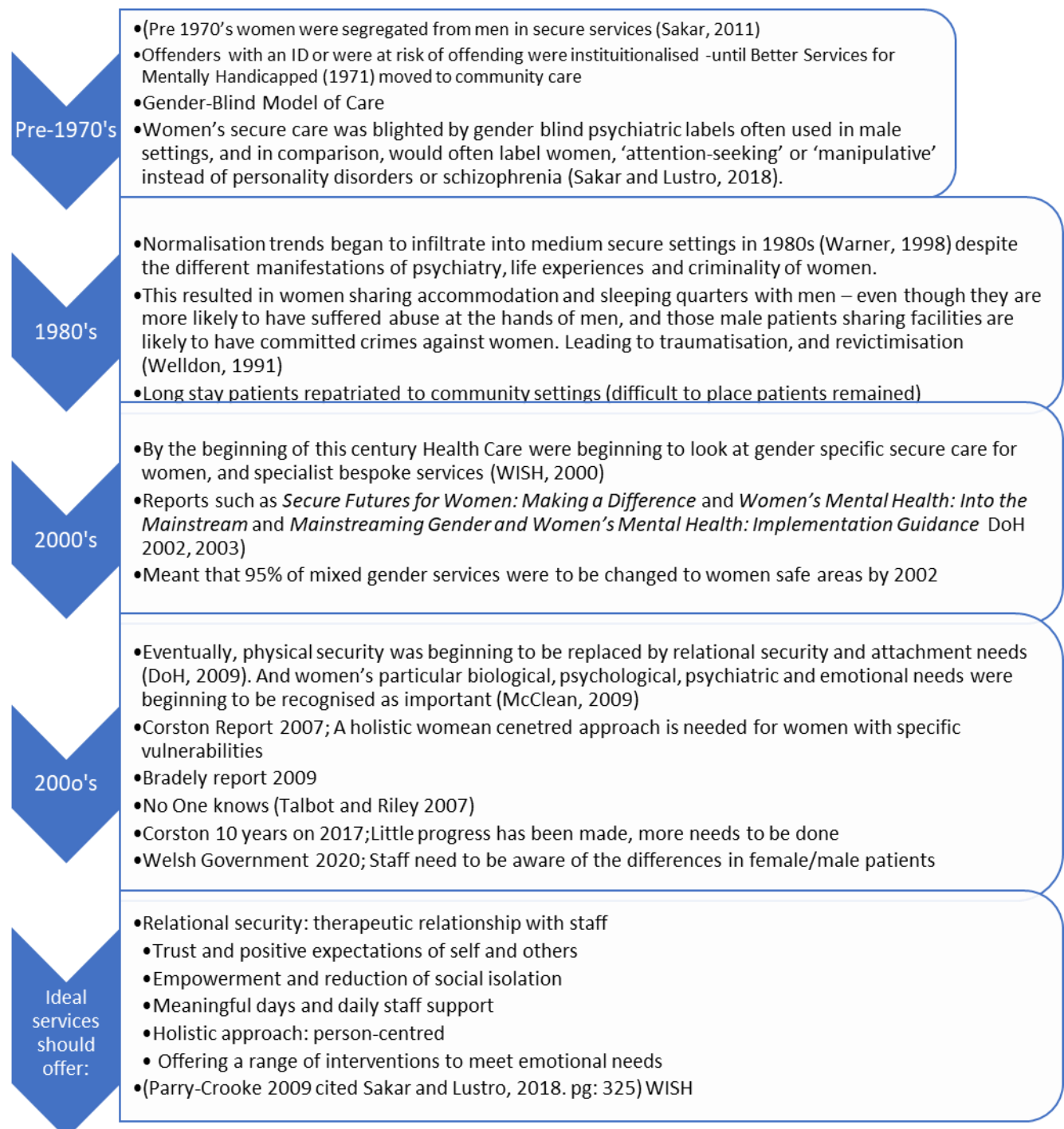
Generally, services for people with an ID have significantly improved over the last three decades since the implementation of The Community Care Act in 1990, with many Victorian-style institutions closing. As a result, there are many success stories and people living the full valued lives they are entitled to. Unfortunately, the ill-treatment of people with ID sadly remains prevalent in contemporary society and abusive practices continue to happen. The nation was shocked when the exposure

of systemic patterns of serious abuse at Winterbourne View hospital (BBC Panorama Undercover Care: The Abuse Exposed 2011), was aired on national television. Following this The Bubb Report (2014) was published and, thus, substantial recommendations were made. The government subsequently published the national plan, Building the Right Support, Homes not Hospitals (NHS 2015) to implement the Transforming Care agenda. Recommendations included the closure of a significant number of in-patient beds and repatriation of patients into community living. Unfortunately, eight years following the Winterbourne scandal similar abusive practices were exposed, this time at Whorlton Hall (BBC Panorama, 2019). In this instance vulnerable adults with ID were once again systematically abused and mistreated.

### 1.8.2 Timeline of Secure Services for Women with Intellectual Disabilities

Historically the development and provision of secure services for Women with an ID has been patchy, sporadic and a continued subject of debate. However, more recently it has been reported that SS continue to fail women, and further development is needed to provide clinically appropriate facilities in SS which is on par with the services provided for men (Sarker and Lustro di 2011). The first recommendation in a Welsh government report said that providers “*should ensure that staff are aware of the differences in presentation and need of male and female patients*”, (Wales National Care Review of NHS LD Hospitals, 2020).

**Figure 1: Timeline of Women's Secure ID Services 1971-2021**



Whilst the national plan is well under way to accommodate people with ID into community living, there remains policy, practice and pragmatic issues outstanding in order to discharge all patients. This means people with ID remain in hospitals when perhaps they ought not to be. This research explores the experiences of the women and the nurses in secure wards, enabling them to tell their story in their own words.

## 1.9 Overview of chapters

Chapter one (this chapter) introduces the topic by providing focus and context of the specific area of the research study, including the aims and objectives and the acronyms used throughout the thesis. The chapter provides a timeline of policy and legislation, the research sites and participant details as well as exploring prevalence of ID and women in SS.

Chapter two, the literature review, presents the current corpus of knowledge in the area studied, and how the literature was searched using an adapted version of Onwuegbuzie and Frels (2016). It gives a detailed account of what the researcher has learnt from previous research and how this research is positioned in relation to current thinking and discussions.

Chapter three, the methodology chapter provides the conceptual framework for the research study. By presenting the methodological approach adopted in the research study it demonstrates the underpinning philosophical and theoretical positions. The chapter will also address the ontological and epistemological position relating to the research study.

Chapter four, the methods chapter gives an account of the research design along with a discussion of the method used in the research study. The chapter will firstly



re-state the aims and objectives followed by the method, including research design, sampling, recruitment, data collection and data analysis. The chapter will conclude with an account of the ethical considerations required for the research study.

Chapter five, the discussion of data chapter, illustrates how the data was generated in the research study and subsequently analysed. The chapter sets out how the analytical approach was thematic analysis, adapted from Braun and Clarke (2006). A detailed discussion is given of what steps the researcher took in the stages of analysing the data.

Chapter six, the findings, and discussion chapter, reveals what has been learnt from the data. It discusses the themes that emerged from analysing the data, illustrating how each theme relates to the principal research question. The chapter includes evidence for what was found with extracted examples from the data of individual direct quotations as said by participants. A discussion of what was found in the data is provided in this chapter in relation to the chosen methodology, which correlates with the objectives of the research study.

Chapter seven discusses how this research has produced an original contribution to knowledge and acknowledges the limitations in the research. This final chapter proposes future directions and recommendations for the women and their families, researchers, staff working in women's secure ID services, educators, and service provision. Challenges encountered in the research are discussed, particularly those arising from the research design and the implications from the findings. Finally, the chapter concludes with closing comments and a reflective account from the researcher.

## 1.10 Chapter summary

This chapter has introduced the research subject and presented the aims and objectives of the research study. The participants and research sites have been presented and a timeline of policy and legislation from a historical to current perspective has been provided. Prevalence of intellectual disabilities and the prevalence of women in SS have been discussed. The chapter concluded with a summary of each chapter in this thesis.

## Chapter 2: Literature review

### 2.1 Context

In a qualitative study, it is crucial for the researcher to be cognisant of the evidence base relating to the subject (Lacey, 2015), and to demonstrate an understanding of the evidence and current thinking about that subject. This enables the researcher to show respect for current thinking yet critique what is known about the topic. A close exploration of the sources was required to support this study in reaching the aims and objectives. This includes articles, journals, government publications, policies and practice reports that relate to the women with an ID and the nurses in Secure Services.

Literature reviews do not only authenticate the study, but place its conclusions in the context of what is already known (Streubert, 2011), defining the research problem, discovering important variables, evaluating previous research, establishing if there are any recommendations or findings that need considering, identifying gaps in current knowledge that can inform the study, preventing duplication of similar studies and finding relevant methodologies and methods (Randolph, 2009; Hart, 1998). This review will show that the evidence base is limited in relation to women with ID in secure settings, illustrating the gap in the literature, and demonstrating that this research study is timely and essential.

### 2.2 Searching the literature.

There are seven steps in carrying out a comprehensive literature review, as described by Onwuegbuzie and Frels (2016 p.84). Reviewing the literature will demonstrate how this research study is positioned with other researchers in the area and will contribute to the current evidence base. The principal question in this research study is 'What are the experiences of women with an intellectual disability within secure services and how do the nurses support them?'. Therefore, reviewing

the literature was restricted to this clearly defined topic. Specifically, women with ID, Nurses and Secure Services.

This study utilised an adapted version of the 7 Steps to a Comprehensive Literature Review (Onwuegbuzie and Frels, 2016), as demonstrated in Table 1 below. At first it appears a linear process although, the arrows between the steps illustrate a relationship between the steps. In the subsequent discussion of the model, it is shown that it is in fact a recursive process.

The process of searching the literature involved following the guidance at step 2 to initiate the search (Onwuegbuzie and Frels, 2016). This provides an audit trail and guiding criteria for the initial search, with five tasks to follow in order to facilitate a comprehensive search.

Table 1: Adapted version of 7 Steps to a Comprehensive Literature Review (Onwuegbuzie and Frels 2016)

<b>Exploration Phases</b>	<b>Steps</b>	<b>Actions</b>	<b>Outcome</b>
	1. <i>Exploring beliefs and topics</i>	Explore key concepts; beliefs; methodologies; philosophies	Focussed Topics and began to structure the process
	2. <i>Initiating the search</i>	Task 1. And Task 2.  Task 3 and 4.  Task 5.	Data bases identified initial search.  Explored abstracts and contextualised information.  Information categorised and organised.
	3. <i>Storing and organising information</i>	Electronic storage and organisation of literature along with researcher notes	Electronic folder relating to themes were created
	4. <i>selecting/ deselecting Information</i>	Strict inclusion/exclusion criteria developed	Data bases and other specific sources searched
	5. <i>Expanding the search</i>	More focussed search expanded	Other specific sources of information identified and utilised
<b>Interpretation Phase</b>	6. <i>Analysing/ synthesising information</i>	Elective coding and Focussed coding utilised.  pertinent literature was compared, contrasted, extrapolated and selected the information	Connections made in the literature to inform the themes, gaps, methodology and analysis of the study
<b>Communication Phase</b>	7. <i>Presenting the CLR report</i>	Identify and communicate gaps in knowledge.  Reflexivity and express conclusions	A comprehensive literature review to inform the study

## Exploring phase

### Step 1: Exploring beliefs and topics.

The beginnings of exploring beliefs and topics were based upon individual experiences, philosophical research beliefs as well as a personal philosophical world view. What was known about the discipline and what was believed about the topic. Literature, policy, NHS provision was explored to focus on the topic as the process was structured. Women's ID secure services, resonated with what I cared about (for further discussion of philosophical research stance, epistemology, and ontology, please see the methodology chapter 3). Here at step 1, background concepts were reviewed, in order to continue the audit trail of a comprehensive literature review. Key concepts guided the initial searches and lead through the five tasks of the initial search (Onwuegbuzie and Frels, 2016).

### Step 2: Initiating the search.

Task 1: Identifying databases and Task 2: Performing a search were merged together in this research study.

Firstly, potential data bases from multidisciplinary, interdisciplinary and across other disciplines were considered. The University library includes pertinent electronic and hard copy information. Search engines, both public and specific to my disciplines and topics were considered. This included searching the databases in health, psychology and social sciences. Searching the literature also included books, journals, policies, podcasts, social media, web sites and library databases. To ensure reliability and validity of the sources, only particular sources were searched, dependent on sources used, methodology utilised, trustworthiness, citing, date and specific relation to the topics.

Therefore, topics related to women with ID, secure services, nurses in secure services, men with ID in secure settings, and women in prison.

### Task 3: Exploring information and Task 4: Identifying key terms

Each relevant abstract and references were read to enable the collection of relevant information about the topic. This enables a list of further articles, not always included in the initial searches, to be identified. Here the information received could be contextualised and placed in its historical and cultural context; important for the comprehensive literature review.

### Task 5: Focusing the search.

Here the inclusion and exclusion criteria words were developed. The information available was categorised and organised into topic sections, and pertinence to this study. A list of key words and phrases were merged, Boolean operators added, and synonyms considered and utilised. To search for women WITH ID OR LD for example as the terms change over time and across cultures and was limited by terms used such as 'NOT prison officers.'

### Step 3: Storing and organising the information.

Although there is software available to organise the literature, electronic files were used and determined by themes related to the research question, aims and objectives. This literature was stored electronically developing from categories to themes. Personal research notes were utilised in this step organised and stored in a systematic way.

### Step 4: Selecting/Deselecting information.

Here it is important to be very clear and produce an audit trail of the literature searched and maintain the trustworthiness of the Comprehensive Literature Review. Throughout this step the researcher had to be judicious in decision making. Therefore, strict inclusions and exclusion criteria were developed and utilised to

focus the search. Searching the literature also included books, journals, policies, podcasts, social media, web sites and library databases. To ensure validity of the sources, only particular sources were searched:

Inclusion criteria:

1. Sources subject to a peer review or had been scrutinised and accepted through an editorial board.
2. Sources must have generalisable qualities or be from similar populations.
3. Similar methodologies utilised.
4. Must be written in English.

Exclusion criteria:

1. Grey sources that have not been scrutinised
2. Blogs or websites
3. Sources without a systematic or literature review or a research base
4. Sources pertaining to similar populations that could not be culturally compared.

The broad search terms used were women, ID, secure settings and registered nurses in publications from 2005 to 2019, which produced limited results. The search terms were then extended to include men, ID, secure settings and prison. It was necessary for this study to utilise more generic literature search terms, such as SS for men with and without ID, for people with mental health issues and women in prisons. Free text searching was utilised to ensure as far as possible there was a solid and broad evidence base. Truncation was used to refine the search and retrieve the relevant evidence, specifically ID/LD/learning disability/learning difficulty/intellectual disability. This technique was used because of the numerous terms and definitions in the field of ID.



The current climate is fast moving and ever-changing, necessitating exploration by searching electronic databases using carefully selected key words. A diary was kept of which search engines were accessed and when, the search terms used, and the results produced. The search engines accessed were Medline, PubMed, ProQuest, ASSIA, ZETOC, Web of Science, PSYCinfo, Google Scholar, Northumbria Research Link (NRL) and Northumbria University Library. The search criteria were; qualitative narrative research, women, intellectual disability, forensic SS, and nurses. Initially the search results were restricted to UK, however, due to limited results the search was widened to include Europe, USA, Canada, and Australia. As well as on-line databases for health, the search included a review of the grey literature as it would reveal results from researchers that have conducted studies similar in nature, and from early career researchers similar to the researcher in this study.

#### Step 5: Expanding the search.

Here traditional literature searches were expanded to enable full a comprehensive and up to date literature review. Utilised focussed research to begin to expand a more focused search across similar populations including those in other western cultures and women's mental health services and prisons. Extra information included exploring works of experts and authors in this field and discussing topics with colleagues in similar fields.

A close exploration of the sources was required to support this study in reaching the aims and objectives. This included articles, journals, government publications, policies and practice reports relating to women with an ID, the nurses and Secure Services that also fulfilled the inclusion and exclusion criteria. This ensured the researcher has access to the most up to date saturation and representation of the literature available.

#### Interpretation phase

#### Step 6: Analysing/Synthesising information.

##### Analysing

A mixture of coding methods were used to analyse the data retrieved from literature searches. Firstly, Eclectic Coding of the data was employed to develop broad themes that informed such as 'Offenders with ID' more Focussed Coding, such as 'Women offenders with ID' and 'Women with ID in secure settings' relating to those themes appearing most frequently in the literature, their methodology and that would inform the study and the development of questions for the participants (Onwuegbuzie and Frels, 2016; p 246).

### Synthesising data

A Literature review requires sub themes synthesised to enable an overall understanding of current topics in the study. Much like a jigsaw, synthesis requires a good analytical base to ensure how the literature fits the current study.

This involved synthesising all the literature found and analysed, by comparing, contrasting, extrapolating, and selecting the information pertinent to this study such as the prevalence, experiences, gender, nursing, clinical characteristics, treatments and methodologies used with this population. Like the jigsaw; making connections among the literature in themes in order to present them for use by the reader and within the study, methods, methodology, analysis and results.

### Communication phase

#### Step 7: Presenting the CLR report

The goal of this Comprehensive Literature Review is to inform the reader of the literature involved in this primary research at the end of the dissemination phase, and identify the gaps in knowledge, as well as informing the researcher at every stage of the research study.

This literature review has been written reflexively and ethically, capturing the voices of other authors and colleagues across this field. Therefore, the audit trail outlined above (a methodology of the literature review) is an important aspect to ensure

transparency, include the topic, context, problem and significance of the literature and organised by the themes from the literature. This comprehensive literature review will inform the reader of the pertinent sources of information. It will compare and contrast sources, identify gaps in current knowledge, express conclusions or further studies needed as well as theoretical and conceptual frameworks. It is presented in the form of pertinent themes important to this study.

### 2.2.1 Offenders with an intellectual disability - prevalence

Importantly, it is questionable whether the number of People with an Intellectual Disability (PWID) in the Criminal Justice System is known at all. Furthermore, prevalence rates rely mostly on populations of men with ID as most of the studies are around this population, and obscure real female prevalence. Evidentially there is a substantial body of research around the types of crimes the men are more likely to commit, and this varies substantially to those crimes the women commit (for example sexual offences). Since the offences differ, the needs, treatment and outcomes also differ and, whilst informative for this small population, reflection is required on the distinct profile of the women as opposed to the men.

It is reported that seven percent of those in contact with the criminal justice system have an ID, equating to 2% of the population (NHS, 2016). Three in ten people were identified as having an ID following assessment on entry to prison (Skills Funding Agency, 2015). Therefore, public bodies are illustrating the gravity of the issue and showing actual prevalence of people with an ID assessed when entering prisons. But this shows how many people have not been assessed properly until their entry into the CJS, and there needs to be help for people with ID before entry to the prison service.

Jones (2007) showed similar findings when the issues around PWID, in the CJS were reviewed, to outline and clarify what the concerns were and offer guidance for

clinical staff and researchers. The author acknowledged that there has been limited research in this area and that prevalence of offenders with an ID is not straightforward; as estimates range from 2% to 40% (Holland, 1991; Lindsay, 2004; Lindsay, Law and MacLeod, 2002; Noble and Conley, 1992). Earlier studies have described two groups who have an intellectual or cognitive impairment and encounter the law. The first group are those individuals who have a diagnosis of ID and are known to services. The second group are those without a diagnosis but who are generally and intellectually disadvantaged compared to the rest of the population. Jones (2007) suggested that precise figures of those with an ID involved with CJS remains unclear because of definitions, social policies and the legal frameworks. Maintaining that those with an ID enter the CJS similarly to the whole population, the difference being that their future treatment depends upon the stage the disability is recognised and to what amount. Authors unequivocally held the view that individuals should be receive the least restrictive environment and the best service provision, and that service evaluation should lead the way as opposed to the current trend of criminalising a mentally disordered offender because of limited resources (Hellenbach *et al.*, 2015). The authors concluded that education is needed within the legal system regarding offenders with an ID. Interesting, as they appear to be able to identify PWID earlier than other services do.

When such issues prevail for men with ID in CJS, the infinitely smaller numbers of women in the same categories, make prevalence even more difficult. Attempts to measure the exact prevalence of women with an ID in SS are made, but most have not relied on a formal IQ assessment. During the 1990's such figures were shown to range from 9% detained in police stations (Gudjonsson, 1993) and 19% of women remand prisoners (Dell *et al.*, 1993) to 2-6 % of sentenced prisoners (Maden *et al.*, 1994). Whereas Beber (2012) attributes the variation in numbers of women with an ID in the CJS to the demographics, specifically where the numbers were drawn from and what specific assessment tools were used. The difference in a standard IQ test or a more qualitative approach which relies on an interpretation of the clinician/assessor, which is still an issue today.

### 2.2.2 Women with an intellectual disability who offend.

Board *et al.*, (2015) evaluated a new ID screening service within a women's prison. Analysis was undertaken relating to the characteristics of women entering prison, rates of screening completion, and time intervals for stages in the assessment pathway. The report found that 198 women were remanded to prison and were subject to 202 assessments, most undertaken on admission or soon afterwards. There were 23 referrals for further assessment and only four were undertaken. Most women were released before these could be completed, yet Board *et al.*, (2015) revealed that preliminary screening is feasible in prison and the relevant referrals would be made to appropriate ID services.

O'Brien *et al.*, (2010) gathered information from referrals to all services for anti-social or offending behaviour. It was found in this study that 26% of the referrals were for women, although this study did not consider this specific data in detail. Furthermore, Dinani *et al.*, (2010) discussed how forensic CLDT offers offender-specific treatments to male patients. However, for the referral rate of under 10% of female patients into the service, it was recognised that the service did not fully meet their needs. What is noteworthy here is that the female population in this study was overlooked, because the priority was on the sheer numbers of referrals for men with ID who required offender specific programmes at a crucial point in their journey.

Beber (2012) found that the most common diagnosis for women was personality disorder, with 78% having dysfunctional family background and high levels of sexual and physical abuse. The clinical characteristics of these women appeared to be milder ID, high levels of violence and deliberate self-harm, and a likelihood of unstable personality disorder.

Lindsay *et al.*, (2004) commented on the limited information on male offenders with ID and the almost negligible material on women. They found that women accounted for 9% of their referrals to SS. Despite this, they reported that it was long established

that women were more likely to receive a psychiatric diagnosis (57%) as opposed to their male counterparts (38%), and more likely to be admitted to a psychiatric service as opposed to a prison than men (Kendall, 2004; Maden *et al.*, 1994). Interestingly, Lindsay *et al.*, (2004) stated that earlier reports on the higher levels of a psychiatric diagnosis in women stems largely from sexism, and a general tendency to medicalise women (Lindsay *et al.*, 2004; Kendall, 2004). The limitations in Lindsay *et al.*, (2004) were noted in the use of a generic diagnostic criteria for men and women. However, the diagnosis itself may be variable due to underlying issues of MH. In the study the referral rate was 10% female offenders with no sexual offences. Overall, the reoffending rate was 16% over 5 years. This supports the notion that once the mental illness was treated the offending behaviour desisted. In this study the authors realised that the numbers were low and proposed further collaborative research be undertaken. However, at time of writing this study was sixteen years old, reinforcing the importance of this study.

### 2.2.3 Experiences of CJS - offenders with an intellectual disability

The importance of their disability and gender place women in this study at a distinct disadvantage, yet research shows that all PWID are underprivileged in the Criminal Justice System (CJS). Lindsay (2011) assessed the research, landscape and impact for PWID who offend, and found them disadvantaged at every stage of CJS, as their disability may affect understanding, coping mechanisms and communication. Further, HM Chief Inspector Prisons (2017) reported that PWID are excluded from prison life and/or offender programmes, which could reduce their sentence and the likelihood of recidivism.

Half of prison staff felt that prisoners with ID are more likely to be bullied (Corston, 2007). Durcan *et al.*, (2014) commented on The Bradley report five years on, by acknowledging the significant progress that had been made following the implementation of the liaison and diversion service, street triage and crisis care concordat. These are important ways to mark progress being made, although further work is still needed to implement the recommendations from The Bradley Report

(2008), particularly the importance of ID awareness for frontline staff in CJS. Further impetus and progress can be seen in formation of The Care Not Custody Coalition (Prison Reform Trust) and the National Federation of Women's Institutes to implement the national liaison and diversion service (PRT, 2017). This is a crucial development in the diversion of PWID away from custodial settings into health however, there is still work to be done.

Howard *et al.*, (2015) explored the opinions and needs of offenders with an ID on their experiences within the CJS. Despite its limitations, this study demonstrated the value of views from offenders with ID, acknowledging them as a poorly understood group. This study adds to the body of knowledge and recognised that much of the previous research had been undertaken from a service provider's perspective. There were only nine participants in the study, limiting its impact, but they reported that the need for emotional support remained unmet and made suggestions such as the need for a timeline of their pathway through the CJS, and the importance of healthcare services and staff. This study concluded by recommending that the views of PWID are encouraged and heard, so that their vulnerabilities could be identified and dealt with, and that CJS staff may learn from healthcare staff.

An Australian study by Chan *et al.*, (2012) explored the human rights implications for PWID encountering the CJS and found that by implementing a case study approach protected the human rights of this vulnerable group. A case study approach included interprofessional working, regular clinical reviews with support plans and sufficient resources to implement those plans. Therefore, the need for PWID to be diverted from CJS to health when appropriate is acknowledged across the literature.

Both the Bradley (2008) and Corston (2007) reports are relevant to this research since the former is generic and applicable mainly to men, whereas Corston highlighted the issues faced by women. Both report on how they set out the trajectory of PWID in the CJS, with Bradley (2009) aiming to rescue PWID from

custody and divert from CJS into the healthcare system that would support and guide the person into a more appropriate pathway.

Recommendations made by Bradley have largely been implemented, whereas for Corston (2007) and Corston (2012) the *Five Years On* report illustrates how there are recommendations yet to be implemented, which demonstrates the need for further work in this important area. However, the finances associated with implementing the recommendations are no longer available.

Beber (2012) explored the development of SS for women with ID to review what is known about their MH needs. It was found that regardless of court diversion schemes, PWID still enter the CJS rather than health settings. However, underreporting of even serious cases makes it difficult to establish the precise figures (Lyall *et al.*, 1995).

Women with ID encounter the same disadvantages of men with ID, yet have further difficulties specific to their gender, such as living in services not designed for them, being mothers, being placed far from home, and suffering the disadvantages of their counterparts without an ID.

#### 2.2.4 Disadvantages of Gender

Women with ID share the same disadvantages as their male counterparts and other women without ID in the CJS, thus making women with an ID dually discriminated against. Studies have shown that women across the CJS and forensic health services receive disproportionate treatment and outcomes to that of their male counterparts (Ribeiro *et al.*, 2015). Services are not designed specifically for them, and they are often held with male offenders who have committed crimes against women and women with an ID. This means that the women receive poorer treatment and outcomes as opposed to men, and they may be admitted to SS without



justification (Ginn, 2013). As a result, whilst in the service they are incarcerated with the men who may have been their abusers in the first instance.

It is noted that women with an ID who have children are nearly 6% more likely to have their child removed and placed into services, as opposed to 0.2% of mothers without an ID, and approximately half of mothers with an ID will lose their child at some point during the child's development (Brown *et al.*, 2018). Unlike their male counterparts, whose female partners tend to take on full parental responsibility, research remains gender-biased, as it focusses on the mother and ignores the needs of the father with an ID (Mayes and Sigurjónsdóttir, 2010). Because of the scarcity of placements available nationwide and a lack of clinically appropriate facilities placed miles from home (Harty *et al.*, 2012), they tend to be readmitted to medium SS for longer periods of time (Sarkar and di Lustro, 2011; Corston, 2007). This makes the burden of travel to their family and friends much more difficult, and further isolates them from their identities as mothers, friends, sister, daughters and as women.

Regardless of the scarce empirical data specifically about the women who have offended, there have been improvements in service provision (Beber, 2012). This has resulted in the creation of specialist services, in comparison to earlier services that were described as 'gender blind' (Sarkar and Di Lustro, 2011). Further impetus is needed from providers of specialist services that aim to maintain the specialist status as opposed to integration with generic services. This supports the notion that there is a need for this transition of services, but more work is necessary to explore outcome measures for the women who have offended (Beber, 2012). Central to exploring outcomes for the women is an examination of their clinical characteristics that affect their treatment and future.

### 2.2.5 Clinical Characteristics of Women with Intellectual Disabilities

Lunsky *et al.*, (2012) considered the legal involvement of PWID in crisis and those without legal involvement. They compared 130 PWID and a history of contact with CJS to 617 without. Generally, it was found that those with previous CJS contact were younger, higher functioning and more likely to be male, living in unsupported environments. The authors concluded that PWID with previous CJS contact were more likely to have police respond to their crises than those without CJS contact.

Similarly, evidence suggests that the clinical characteristics of women with ID are complex, and those who are placed in SS are more likely to have a milder ID, have high levels of violence, deliberate self-harm, and a likelihood of unstable personality disorder (Beber, 2012). As well as the fact that their needs are not likely to be well met (Lunsky *et al.*, 2011). Specific diagnoses may include conversion disorder, which is a condition with physical symptoms of a health problem but without illness or injury to explain it (webmd.com 2020).

In their Canadian study, Lunsky *et al.*, (2011) explained PWID and co-existing MH issues with contact with CJS are especially complex and challenging, with scarce and only descriptive research to draw from. Their study included 60 males and 14 females and is the first empirical study to examine the needs of PWID that have and have not contact with the CJS. They concurred with previous studies that PWID with CJS involvement are typical of a PWID without it in terms of age, length of stay, marital status and employment. However, those with forensic involvement present with more severe symptoms and fewer resources than other forensic patients. The study found that these patients required increased levels of care and were more likely to be younger, male, have shorter stays and a personality disordered diagnosis, and less likely to have mood disorders than those with an ID and no CJS

connections. They supported the notion that neglect, and abuse are experienced by this group, as classically described by Day (1988).

Despite the low numbers of women in the study by Lunskey *et al.*, (2011) the researchers noted the rates of sexual (50% vs 17%) and physical (50% vs 20%) abuse amongst women opposed to men. This clearly demonstrates that this is one-way women with ID differ from their male counterparts, and one with significant implications for clinical practice. The researchers held that abuse and neglect should be included at the screening stage and indicated that further research should be undertaken in this area to assist service planners. Therefore, the women's characteristics and history of abuse have significant consequences for their prognosis and treatment.

#### 2.2.6 Historical experiences, sexual abuse, and the effects on clinical characteristics

A learning disability is classified in the Diagnostic Statistical Manual V (DSM 5) as a neurodevelopmental disorder and the presence of intellectual difficulties, deficits in adaptive and intellectual functioning, the onset of which must have taken place during the first two decades of life (American Psychiatric Association, 2013). This classification centres on daily living skills as opposed to an IQ range. This supports the belief that the women are more likely to have encountered services at a young age and may not be able to live independently. The inability to diagnose from a young age, utilising the term global developmental delay, may have exacerbated the issue. Had there been a firm diagnosis, identity established, and a treatment plan arranged perhaps the engagement with SS may not have materialised at all.

Psychiatric disorders accompany children with mild ID, as 80.2% had at least one lifetime comorbid psychiatric diagnosis. Attention deficit hyperactivity disorder (64.9%), oppositional defiant disorder (21.6%) and anxiety disorders (18.0%) were the most common comorbidities, illustrating greater awareness required regarding comorbidities to assist in treatment and rehabilitation (Tural Hesapcioglu *et al.*,

2019). This is relevant to this study since women with ID in SS are more likely to have a mild ID.

It is widely known that adults with ID experience more health inequalities and premature death than the non-ID population (Barnett *et al.*, 2012; Emerson *et al.*, 2006). Similarly, PWID are more likely to suffer from co-existing conditions (two conditions in addition to having an ID). Research found that there is an increased incidence of multi-morbidity of adults with ID and that the extent of co-morbidity in the group aged 20-25 are similar to the non-ID population aged 50-54 (Cooper *et al.*, 2015).

Sexual abuse (SA) and abusive relationships are common in PWID. A study of nine women was undertaken in Australia. It used a narrative approach to explore how women with ID understand sex, relationships, and SA (Eastgate *et al.*, 2011). An interview outline was used to prompt the discussion, during which participants in the study disclosed accounts of severe and systematic abuse during childhood and adult life. The sequelae of abuse were highlighted as an important factor in understanding sexual relationships and sexual abuse. Specifically, this included the inability to have sexual intercourse, fear of sex and avoidance of relationships, impacting on their understanding of same sex relationships, that varied from nothing to fair.

It is known that women are more vulnerable to SA than men, and PWID are three times more likely to be sexually abused, impacting upon the psyche, relationships, confidence, health and mental health of victims (Eastgate *et al.*, 2011). Women with ID have at their disposal far less ability to seek out and engage fully in treatments for the effects of SA, therefore may become multiple victims and suffer enduring mental health issues (Northway, 2013). The literature appears to highlight the prevalence and complexity of women with and without ID that have been victims of SA. Interestingly, women also may be perpetrators of SA.

Studies suggest that as high as 60% to over 80% of women prisoners with ID report being the victims of SA (Alexander *et al.*, 2010; Lindsay *et al.*, 2004). An audit of referrals to a secure setting stated that of female referrals, 81% reported SA in childhood, 66% had a diagnosis of personality disorder and all referrals reported self-harm (Beber, 2012). Interestingly, a third of this sample were referred because of assaults on staff. This study is important as it is English and shows not only the rates of abuse reported, but the psychiatric harm that is often imposed on women in these circumstances.

### 2.2.7 Treatment interventions for women with an intellectual disability

Trauma informed care (TIC) is an emerging intervention within ID services. Keesler and Isham (2017) undertook a study in day services for PWID. A preliminary conceptualisation was undertaken to assess the impact of implementing TIC with service users and staff in America. They found an increase in choice and empowerment amongst the service users, a significant reduction in challenging behaviour and increased satisfaction amongst the staff. They highlighted the need for further studies in this area.

Truesdale *et al.*, (2019) explored the views of specialist practitioners in ID services in the UK, particularly investigating how specialist health practitioners addressed trauma. Twenty-five semi-structured interviews were undertaken across six health services, and the findings indicated that advances in the evidence base was needed for effective psychological interventions for PWID. Specifically, it was argued that further training and education were vital factors for TIC and service development.

Hellenbach *et al.*, (2015) undertook a systematic review of the literature with a focus on psychosocial therapies for women with ID in forensic healthcare. Referring to four studies from 2001 and 2012, they found CBT to be useful in resolving problem behaviour, although their conclusions asserted that there was a significant gap in relation to evidence-based therapies, and that more research is required with an

emphasis on women with a dual diagnosis who present with challenging or criminal behaviour. They also argued that to deliver successful evidence-based practice for these women, knowledgeable and skilled practitioners were crucial.

#### 2.2.8 Service provision in health

The forensic care pathway for adults involved in the CJS (RCP, 2014) highlighted the core dilemma in the provision of care for PWID who offend, as to whether individuals be managed in CJS, generic, forensic MH or specialist services. This paper recommended that health professionals should facilitate training for police officers, custody officers and community support officers, including members of the judiciary and probation service. Particular attention was drawn to commissioning services as close to the home area, as well as offering a range of community or in-patient services to enable a safe and least restrictive treatment.

Davis *et al.*, (2015) considered legislation that enables PWID to be diverted to community-based rehabilitation, as opposed to the previous system where diversion from CJS was admission to hospital. This is the first research study evaluating compulsory community forensic care for PWID from the perspective of a service user. They conducted semi-structured interviews with ten male participants and identified themes from the data, highlighted as taste of freedom, not being in control, getting control back, loneliness, and feeling like a service user. Essentially, this work was about relating positive and negative accounts of community-based rehabilitation. The participants had some difficulties with communication and the design also presented some limitations as the sample size was ten and all were male. They recommended strategies to improve the model through clarity in service and roles, with clear pathways and relevant support. They suggested appropriate training and support for staff and further research to elicit the views of professionals of what would help them in their role.

Lindsay *et al.*, (2006) conducted a comparative study of two male cohorts of sex offenders ( $n=121$ ) and other types of offences ( $n=105$ ) and female offenders ( $n=21$ ). This research is the most inclusive exploring a community service for offenders with ID. There was a four-year follow up for sex offenders, a seven-year follow up for sex offenders and other offenders, and a consideration of characteristics among female offenders. They suggested that the forensic ID community service may have an impact on recidivism. Noteworthy here is that the female offenders had exceptionally low recidivism, except for prostitution offences. Prostitution offences could have been described as an acquiring offence, in that the women were sourcing finances to feed themselves or their family. Additionally, prostitution-related offences will have a link to sexual exploitation of the women.

Benton and Roy (2011) focussed on the first three years of a community forensic service for PWID in Birmingham. The authors acknowledged that institutional closure prompted service reconfiguration and the growing need to balance public protection and a least restrictive environment for PWID. They supported the notions that hospital admission is not always appropriate and that forensic service models should include a range of options and outlined the importance of a specialised Community Forensic Team (CFT) to maintain the least restrictive environment. A range of therapies were provided for problems including sexual issues, fire-setting, anger management and assertiveness. This highlighted the success of inter-professional working with mental health teams, forensic MH teams, probation, courts and the police. They concluded that this service model met the needs of PWID, reduced risk and provided a high-quality community service. This has implications for this research through exploration of the range of services and therapies that PWID are engaged with and any impact.

The operating model of the national liaison and diversion service is being piloted across 26 sites, with the aim is improve screening, assessment, and referral of vulnerable people in the CJS (NHS England, 2014). MacMahon and McClements, (2015) outlined two models of forensic service delivery, integrated and parallel. The authors discussed the term 'forensic' service user to be under mental health

legislation and within involvement with criminal justice services (Scottish Executive, 2003). Conversely it has been claimed that there is no such person as the forensic patient (Mohan *et al.*, 2004). The authors discussed the issue of terminology and the distinction between offending behaviour and behaviour that challenges, the presence of the requisite mens rea as evidence of intent seems to be the deciding factor, where the lack of intent may be suggestive that the person with an ID had no malice aforethought. The authors stressed the difficulty in not being able to treat a person's ID, which may mean a person remains in forensic services longer than necessary. The authors suggested the use of the integrated model and to embed forensic services within the generic team. This in turn will increase the skills of all clinicians working with offenders with an ID. However, they seem to disagree with most specialist studies in this area that highlight the need for specific services for women, and staff specifically skilled to work with this vulnerable group.

Taylor *et al.*, (2016) considered the impact on service provision as a result of Transforming Care: A National Response to Winterbourne View Hospital (Department of Health, 2012). The authors examined the rapid closure of beds (35%) and minimal service provision in the community, acknowledging that there has been inappropriate hospital admissions for some PWID. They proposed that PWID need longer treatment plans and will not be best placed in the prison system. Further, they believe that the introduction of Transforming Care (TC) will increase the admission to independent sector hospital beds, as national NHS beds reduce. This is despite the fact that TC was implemented to improve quality of care, quality of life and increase community presence (NHS England, 2017).

One of the specialist teams operationalising the TC agenda is the Secure Outreach Transitions Team (Tees, Esk and Wear Valleys NHS Foundation Trust), covering a population of 1.3million. The caseload of this team is 81, with a staffing compliment of approximately 24 (NHS England, 2017). This indicates a problem, where the ratio of 1 staff to 3.4 service users is unworkable, particularly as a service user may require up to three staff at any one time.



### 2.2.9 Nursing in the UK

There are currently four types of Registered Nurse (RN) in the UK; Registered Learning Disability Nurse (RNLD), Registered Adult Nurse (RN -A), Registered Mental Health Nurse (RN-MH) and Registered Children's Nurse (RN-C). All are educated in higher education institutions (HEI) over a three-year programme leading to a BSc Honours and registration with the Nursing and Midwifery Council (NMC). There are currently nineteen HEIs in England providing BSc Registered Nurse (Learning Disabilities), including the Open University. This is in comparison with over one hundred courses relating to the other fields of nursing from fifty-three HEIs ([www.UCAS.com](http://www.UCAS.com)). The UK and Ireland remain the only countries providing this course. This shows that nursing - learning disabilities, has the lowest numbers in course provision and availability across the higher education sector, with a steady decline in numbers of those applying, which was acknowledged in 2013 (Gates and Statham 2013), and more recently in 2018, (Mitchell, 2018). The steady decline in numbers over the years of student Learning Disability Nurses points to a diminishing, potentially unstable workforce.

Nurse education moved from hospital-based training schools to universities in 1999, and subsequently to an all-graduate profession in 2015. Previously there were opportunities for NHS employees at HCA grade to be seconded to education for RN programmes. This model remains in place; however, it is currently fragmented, disparate and has a low uptake. However, there are emerging alternatives to achieve RN status, for example trainee nurse associate (TNA) or degree nurse apprenticeship (DNA).

### 2.2.10 Learning Disability Nursing in the UK

Learning disability nursing is a unique strand of nursing and requires specialist skills and training (RCN, 2019). RNLDs work across the age continuum in community, liaison, primary health, social sector, criminal justice system and SS (Manthorpe *et al.*, 2004). There are 17,174 RNLDs in the UK and 3,244 (20%) are employed within

the National Health Service (NHS, 2019), as opposed to 5,553 in February 2009 (nhs.digital, 2019). The remaining 80% are employed in private companies, the community, education and prisons.

This means that the number of RNLDs working in inpatient and secure units has dropped by nearly 60% in ten years (RCN, 2019). Following the withdrawal of student nurse bursaries in 2016 there was a 60% decline in applications to RNLD and some universities saw a 75% reduction in applications and consequently withdrew the programme completely (London Southbank and Leeds). Despite the glaring reduction in the number of RNLDs, there remains over 1.5 million people in the UK who have an ID, with this figure is set to rise (NHS, 2018). Strengthening the Commitment (Scottish Government, 2012) recommended that all organisations who commission, deliver or develop nurse education should generate nurses with the necessary skills and competencies to support PWID.

As a recognised and distinct area of nursing, RNLD has developed and responded to policy changes throughout the last 100 years and has been highlighted as a compromised workforce with the numbers working in the NHS decreasing from 12,504 in 1995 to 6,600 in 2009 (Gates, 2011). As a professional group, RNLDs have been proactive to scandals such as Ely in 1979, Winterbourne in 2011 and Whorlton Hall in 2019, all gathering national support and government impetus. However, in 2018 it was reported that the number of RNLDs were at the lowest of all nursing fields, despite being the specialist practitioners to support PWID, and NHS Improvement implemented standards for Trusts (NHS, 2018) to employ liaison and health facilitation RNLDs. Sir Jonathan Michaels' report Death by Indifference (2008) gave the damning evidence that PWID were dying as a result of inadequate healthcare in acute services, stating in Recommendation 1 that training in ID for all health care staff was compulsory. However, there is still work to be done, and the specialist area of treating women with an ID in Secure Services is no exception.

Twenty years ago, the regulatory body for nursing, The United Kingdom Central Council for Nursing and Midwifery (UKCC) now known as Nursing and Midwifery Council (NMC), stated there was insufficient knowledge about forensic nursing and a lack of definition of the skills required (Dalgarno and Riordan, 20214; Department of Health, 2007). Strengthening the Commitment (Scottish Government, 2012) notes that nurses need to have the skills to work in a forensic environment, but there remains limited specific research relating to this (Mason *et al.*, 2010). There is international work on forensic psychiatric nursing, but very little on the role of forensic RNLD, excepting the work by Storey and Dale, (2001), Inglis (2010) and Lovell, (2017).

Mason *et al.*, (2010) explored role perception between forensic and non-forensic RNLDs, via four hundred questionnaires with a response rate of 46% from secure and 49% from non-secure settings. The study measured responses across six themes and found a statistically significant relationship across all five. The study found that there is only limited difference in perceptions of the role constructs between forensic and non-forensic learning disability nursing. One theme which did not show a significant difference was fear-confidence construct.

It has been noted that educators do not have sufficient knowledge and are not preparing nurses to adequately work in SS (Storey and Dale, 2001). The phrase 'flung in at the deep end' or 'left to sink or swim' has been commonly referred to in the literature and supports the notion that newly qualified nurses are not adequately prepared to carry out their role effectively (Horsburgh and Ross, 2013), with a significant gap between theory and practice (Whitehead and Homes, 2011). The evidence furthered the support to implement a national preceptorship programme which was implemented in 2000. However, it remains that the little research in this area points to specific skills and characteristics required by RNLDs to work in this small but significant specialist area.

### 2.2.11 Characteristics of staff in secure settings

Dalgarno and Riordan, (2014) reported on a limited body of research exploring the views of RNLDs in forensic settings. They explored the lived experiences of RNLDs and their views on forensic practice as a specialism. They found this area of practice was perceived as the same yet different to generic nursing. The nurses in the study reported on person centredness and their skills to help patients develop for discharge. They recognised that their role was likened to walking on a tightrope, and this affected their emotional well-being. Whilst this study gave a voice to some RNLDs it offered advice for further research in this distinct area of practice. Furthermore, a possible area for future research could explore the journeys of nurses and patients as they parallel each other.

Hepworth and Williams (2015) collaborated with a young person who was known to youth offending team (YOT) and their family. The paper sought to identify how the skills of a RLDN contributed effectively to inter-professional working in a YOT. The paper discussed unmet need and how a young person entering the CJS has additional and complex needs. The authors highlighted a lack of evidence in relation to women with ID entering the CJS. The RNLD has the skills to tease out the issues and identify support mechanisms and advise the court of what the support should be.

Inglis (2010) compared the 'good nurse' characteristics from the literature to those of RNLDs working in SS. She reported that this role is a complex (as did Lovell, 2017), and one that is underpinned by core values, knowledge, skills and personal characteristics and necessity. The secure and therapeutic skills required co-exist among staff in these settings, and they enjoy warm and therapeutic relationships with the PWID that they care for. Limitations of this research for this study include being distinctly about men with ID, but its qualitative nature and inclusion of staff relationships and skills lend themselves to the current study.

Clarkson *et al.*, (2009) examined the perceptions held amongst a group of PWID about their support staff. This study built on earlier work on the experiences in specialist and generic services. The authors identified the need to reflect a service user voice, rather than favouring the views of those asking the questions (Coffey, 2008). They recruited in-patients who had an ID and had offended or were at risk of offending. The results indicated two superordinate themes, staff relationship factors and staff attributes. The analysis presented data which was consistent with earlier work in that there was a variation of experiences across populations. Participants spoke about how they appreciated consistent, familiar staff with whom they could develop meaningful relationships based on honesty, trust and caring attitudes. In the presence of these attributes' participants felt physically and emotionally protected. Whereas immaturity, inexperience and short temper had led to increased discontentment and were viewed as unsupportive, thus creating a sense of frustration and vulnerability amongst the participants. A continuum was described in the study and participants placed staff at the end of newly employed and inexperienced. At the other end of the spectrum were staff who had been employed for long periods. Maturity provided experience and increased understanding of patient need. It was suggested in this study that burn out, stress and low morale may contribute to perceived lack of motivation.

There is an abundance of literature around the welfare of staff, (Rose *et al.*,1998; Hatton *et al.*, 2004). Hastings *et al.*, (2004) researched the well-being of staff in ID services, specifically the assessment and connections of burnout by using the Maslach Burnout Inventory (MBI). It found that adopting the MBI was extremely pertinent for staff in the ID service.

#### 2.2.12 Listening to women with intellectual disabilities

Fish (2012) reviewed literature over the last thirty years relating to the women who access SS. This review focussed upon direct quotes from the women. The review identified that until recently women with ID have been excluded from opportunities to contribute to social policy. Fish (2012) reviewed literature around aspects of secure

care and highlighted that the needs of women in secure settings are complex and often different to men because of their life experiences. There appears to be a range of literature supporting the notion that women are unsuitably placed in services intended for men. Fish (2012) concluded that the literature, including the voices of women with ID, shows positive attributes, such as the women actively asserting their own identity as opposed to the role bestowed on them in an institutional setting. Similar to the work of Fish (2012), this research study listens to the accounts of the women in their own words.

Gjertsen (2019) found that participants with ID speaking for themselves adds gravitas to the data, although there are methodological and ethical considerations that cannot be overlooked. This means a researcher needs to proactively include participants whilst being aware of the inherent dangers of involving those with an ID. These include, for example, social desirability, acquiescence, suggestibility, eager to please or saying what they think the researcher wants to hear (McVilly *et al.*, 2006).

Kirby *et al.*, (2015) considered inclusion and participation of service users to give feedback in terms of service provision by conducting a survey within a community forensic service in Birmingham. They questioned the level of consistency and methods used to meaningfully collect feedback. They highlighted the importance of service user involvement to promote partnership working with PWID who have offended, due to the intrinsic value of service users taking accountability for the consequences of their behaviour. In the study conducted by Kirby *et al.*, (2105) he researchers contacted 47 service users and a total of 28 responded. Exclusions were made in relation to contraindications in care and treatment, for example lack of engagement and instability of mental health. Progressive outcomes of service improvement from feedback were embedded into practice.

Conducting semi-structured interviews with women with an ID and the nurses in the same research project is not widely accepted in current research. The women have restrictions placed upon them, which makes them a hard-to-reach group. In essence

this means interviews could only take place within certain areas within the study site. The reason for this is because the women were in SS and detained within the remit of the Mental Health Act, (1983 as amended), by virtue of treatment, assessment, criminal and/or challenging behaviour (Duke *et al.*, 2018). Undeniably the women have encountered the criminal justice system (CJS) and are in security as a result. Importantly, women with an ID have very real and specific disadvantages because of their background, psychiatric history, relationships, treatments and placements offered to them, and this makes their situation and care/treatment more complex.

Accordingly, such women are rarely offered a chance to take part in the development of the services and policies apparently designed to meet their needs, which is relevant because of hospital closures and an increase in community living following The Transforming Care agenda (Department of Health, 2012).

#### 2.2.13 Listening to Registered Nurses

Wilson *et al.*, (2018) explored the views of Australian nurses working in ID settings about the uniqueness of their role. This study gathered data using semi-structured interviews and analysed the data using thematic analysis. Themes from the study found that participants acknowledged the unique investment in the nurse patient dyad, the role of ID nurse was a bridge between disparate systems and finally the role of the ID nurse had an ambiguous future. The researchers also acknowledged the specific recognition of the field of ID nursing as distinct and much needed, as in the UK model of a specific field of ID nursing. The problem with the study, however, was the nurses who were participants were not educated or trained specifically to be a RNLD. The Australian model is a generic programme of learning for all nurses, and only at the post-qualifying stage is the field of work then selected. As discussed earlier in this chapter, there are four fields of nursing in the UK, learning disability/mental health/child/adult. All are educated in an approved higher education institution, studying a chosen field of nursing from day one of their course.

## 2.3 Chapter Summary

This chapter has contextualised the study within the current body of literature and has shown how literature was located, reviewed, and critiqued from the evidence base. The chapter has shown how literature was included from a wider evidence base than that directly related to the topic of this research. The chapter has shown the limited evidence base in relation to women with an ID in SS, and a similar picture of the nurses who support them in SS. The chapter has discussed the issues around similar populations, whilst illustrating that no research was found which included women with an ID and the nurses in SS. This therefore provides the springboard for further research, such as this work, wherein an innovative and creative methodology can be utilised to develop the evidence base for women with an ID in SS and the RNs who support them.

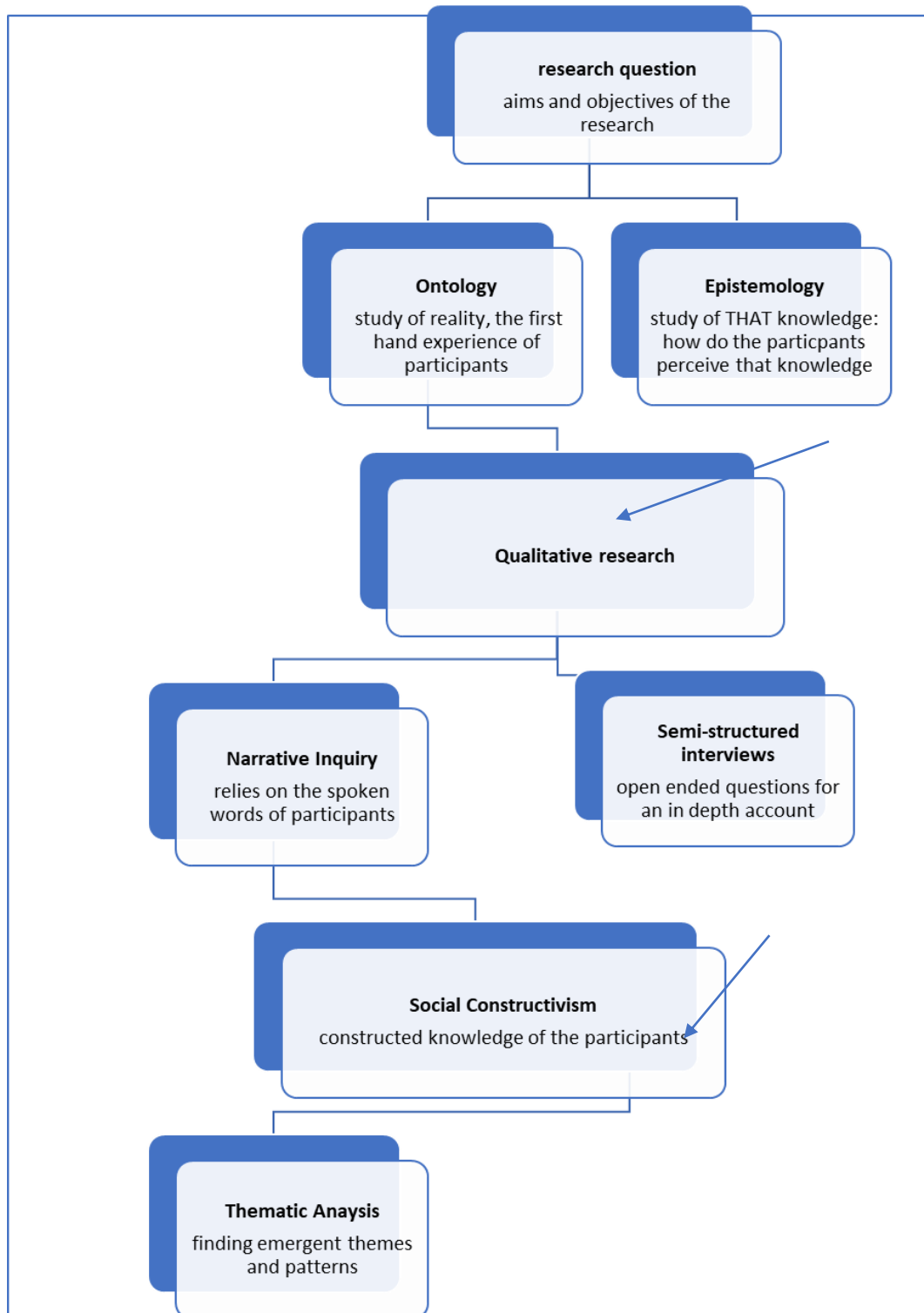


## Chapter 3: Methodology

### 3.1 The conceptual framework

A conceptual framework is the overarching methodological approach used in a research study, which was timelessly described as ‘the researcher’s map of the territory being investigated’ (Miles and Huberman, 1984:33). A conceptual framework comes from the intellectual thinking on which a study is based. In this research study the approach was interpretivism. Figure 2 below is a visual representation of the conceptual framework applied in this research study.

**Figure 2: Visual representation of the conceptual framework**



### 3.2 Methodological approach

Methods in research are based upon philosophical (methodological) issues which help the researcher make decisions about the research and base those decisions into paradigms (Clarke, 1998). Methodology was classically described by Guba and Lincoln (1994) as the overarching theory of how we get to know the world and gain knowledge from it. This research study explored what the experiences were of the women and of the nurses who support them, therefore it was inductive in nature as opposed to deductive. Therefore, the approach best suited to this research was qualitative, within a philosophy of interpretivism, since interpretivism is an overarching term used to group together social constructivism, phenomenology, and hermeneutics.

### 3.2.1 Philosophical approaches to methodology

The overarching philosophy for this study is one that lends itself ideally to qualitative methods. The question posed in this research study was ‘what are the experiences of women with an ID of secure services and of the nurses who support them?’ Therefore, the most appropriate overarching approach for this research study was qualitative in nature. This is because a qualitative approach to research is related to lived experiences, supporting the notion in this methodology that there are many truths to uncover, taking an interpretivist perspective.

According to Clarke (1998), philosophy is the basic level to examine methods of enquiry. When taking a philosophical stance, one makes assumptions about the world based on one’s own beliefs. Theoretical concepts have been defined as a conceptual framework which supports and informs a research study. This then is a way of presenting in words, or in visual format, the main issues which are being studied (Miles, Huberman, and Saldana, 2014). Figure 2 above provides a visual representation of the methodological thinking; the paradigm applied to this research study. Furthermore, the conceptual framework relates the key factors, or constructs, and the presumed relationships within those factors (Maxwell, 2013). Thus, concepts, assumptions, expectations, beliefs, and theories guiding the research study, were a major factor in the design.

In this research study reality exists within the conceptual framework, in the context of cognitive frameworks, which created frameworks for thinking about realities (Guba, 1997). Ontologically, there are no facts, therefore, there is no realism, just relativism. Epistemologically, this sees knowledge as a human construction which is shaped by interactions between the researcher and those they study (Guba, 1997). It is apparent therefore that research cannot be value free, as it is viewed through value windows. Therefore, many constructions of the world are possible. These reflections or social interactions taint how the world is seen, and even though they are socially constructed, they are seen as real forms of social interaction in this context. However, they are not real "facts", only constructions. This leads methodologically to identifying many constructs which are then brought together to form a consensus, which is done in two main ways, hermeneutic and dialectic. Hermeneutic aspects include attempting to describe individual constructions as accurately as possible. The dialectic aspect includes comparing and contrasting each individual's construct so each subject is aware of those of the others and can perhaps "come to terms with them" (Guba, 1997; 26). This is the logical discussion of ideas and opinions. Both methods combined aim to produce accurate and sophisticated constructs, taking into account that the research does not claim to predict or control, but to "reconstruct" the world. The methods that are used here include those which construct knowledge through the researcher and the participant interacting, using their narratives or storytelling.

Social constructivism is important to this research because the study aims to explore the experiences of the women and the nurses, hearing how they view their journey, what works well and what could be better. It hears first-hand how the women came to be there, where their best relationships are and where they get the most support. Furthermore, it also explores how the nurses support those women, what a typical day looks like and how prepared they were to support the women. This theory therefore has utility in examining human development as being socially situated, with the knowledge and narrative being constructed through interaction with others. This research explores how the women, and the nurses see their experience of SS, by

listening to their actual and perceived knowledge of the reality of SS. It aims to find out how the women view their experiences, how the nurses were prepared for female SS, and whether the women and the nurses have the same view about SS. Was it positive or was it negative, did they both learn together? Did their previous experience shape their views, assumptions, and expectations of SS?

The theoretical framework in this research study is informed by existing theories and concepts that are relevant to this research, which are theories of power and control. This, therefore, relates to the broader areas of knowledge and understanding of power and control of the women and the nurses, because the research aimed to explore the experiences of the women and the nurses. This includes their actual experiences, how their experiences led them to being at that point in their lives, and how they viewed their experiences and journey so far. The chosen approach to extrapolate this data from the women and the nurses was narrative. Semi-structured interviews were developed and incorporated to capture data from participants with a view to delve deep into the accounts of the participants, from their own words, as will be discussed in section 4.4.

A paradigm is difficult to define, according to Guba (1990), but consists of three basic elements. First, is the ontological question, what is the nature of knowledge? Second is the epistemological question, what is the relationship between researcher and knowledge? Third is the methodological question, how do we find this out? These represent belief sets which form paradigms which may be adopted by researchers in order to create a framework for defining and answering questions, or for beginning and guiding inquiry.

***The ontological question: What is the nature of the knowledge?***

This research is exploring the experiences of the women and of the nurses of SS. Ontology is described as the study of reality and of human beings (Guba and Lincoln, 1994). In this case, it asks the question of the nurses ‘how do you support a woman with an ID in SS?’ and also asks the women ‘what is your experience of female SS?’

***The epistemological question: What is the relationship between researcher and knowledge?***

The knowledge sought in this research study is from a professional lens, a lens that encompasses a legal, nursing, academic and researcher-related background. It seeks to find out about how the women view their experiences of SS and of how the nurses see their experiences in supporting the women whilst receiving care, support, and treatment in SS.

***The methodological question: How do I find this out?***

This research study listened to the accounts of the women and the nurses to hear their experiences and learn how both groups of participants view their experience of SS.

### 3.2.2 Social constructivism, post-modernism, post-structuralism

Constructivism is a philosophical perspective with a proposition that individuals construct and interpret their social world in certain contexts (Schwandt, 1997). In this research study the women and the nurses were able to tell the researcher how they construct and interpret their social world. Constructivism is a philosophy, or theory of knowledge, developed by Piaget (1968) who believed that personal knowledge is adopted by each person. The theory of knowledge is therefore applicable to this research study insofar as the women and the nurses were asked to give an account of their experiences of SS as they see it, from their own lens and their own perspective. In addition, it is argued that the knowledge we gather comes from our experiences. This (constructed) knowledge is then stored with existing knowledge. However, constructivism suggests that existing knowledge dictates how we deal with new knowledge (Maltby *et al.*, 2010).

Constructivism emphasises the view that we are constantly accommodating and reframing what we know within the biological and developmental processes of the human mind. In essence Piaget (1968) was alluding to the nature versus nurture debate. This debate has two basic strands; the first is radical constructivism, which is

concerned with how things are known to the individual, and their cognition. The second strand is known as social constructivism and concentrates more on interactions and the social process. Thus, the researcher is exploring social situations and interactions to understand how participants in the research come to share an understanding of the social world. The nurses in this research study share their interactions with the women and vice versa.

Social constructivism combines constructionism and constructivism, in the manner of examining meaning, language and thought. In short it is an active learning process. Social constructivism suggests that it is the individual learning that takes place because of interactions in a group. Therefore, reality is a constructed concept. Human development is socially situated, and knowledge is constructed through interaction with others. This perspective is closely aligned to this research study since it enables the researcher to understand:

- What the women and the nurses know
- How the women and the nurses know what they know
- How they see their experiences
- How this has shaped their experiences of secure services.

These were all questions which the methodological approach was designed for.

Social constructionism points to the assumption that personal meaning making for women with ID is socially and contextually constructed and influenced by social practices and interactions (Bhaskar *et al.*, 2018). In the case of this study, norms and expectations have been set within secure environments for much of the lives of participants. Their individual stories span decades in some cases and involve several geographical moves, which may be both positive and negative in terms of both leaving behind friends or being freed from association with individuals or cultures that may be harmful. What unifies the narratives is each woman's view of and aspirations for the future, as well as their constructions of the past and present. Therefore, the analysis of the narratives was thematic and authentic, foregrounding the personal stories of the women and prioritising them over pre-determined

theoretical frameworks or constructs. Therefore although 'power and control' or 'feminism' may be relevant lenses through which to interpret the data, the authentic stories of the women were extracted from individual non-chronological conversations and presented in terms of a collective past, present and future to bring their stories and their meaning together. The analysis was more than a description of events, it also made sense of why the story was told in a particular way (Fleetwood, 2016) and allowed others present in the interview to input into it.

There is not one specific methodology or method that makes a piece of research 'feminist' (Beetham and Demetriades, 2007). The framing of these women in terms of their ID, their offending behaviour, their sexual activities, and preferences are all as relevant to understanding and highlighting their lives as is their gender. The experience of having ID and being female undoubtedly brings gendered expectations for social behaviours and arguably makes them more vulnerable to abuse and as women, and as people with ID, they are marginalised, and some would argue oppressed. However, the key classical aspect of feminist research - to catalyse and argue for social change and argue the narrative through the lens of oppression, was not the core perspective of this thesis. The aim was to hear from the women about their experiences as they see it and to provide an opportunity for them to do it in their own words.

### 3.2.3 Power

Power is created through knowledge (Foucault 1982) and that knowledge disciplines us. It is that discipline that creates dominant discourses and ideologies that determine what is normal/abnormal -right/ wrong. Such influential ideologies tell us how to treat others who are outside of acceptable norms. In essence, this created the power to institutionalise people with ID, remove them from families, communities, and support systems.

Although, discourse is more than a conversation, it can be said to reflect power, and it allows the powerful to achieve dominance in policy and service areas (Thompson, 1997). It is the way the world and its problems are formulated, the perspectives on



those problems and the solutions to the problems. Therefore, its importance when discussing PWID is vast.

Discourse may be used as a tactic in political arenas and can be useful for those wishing to promote certain policies and values, and rarely are those used by PWID. However, there may be similarities with the Foucauldian panopticon, where Foucault espoused the freedom of people. Yet, we know that the discourses of everyday life can be affected by power and the producer of reality to others in a disciplinary situation. Whilst not a negative, power can be the producer of reality about people in systems of control to produce knowledge (Foucault, 1980).

From a contemporary standpoint the balance of power in the lives of people with ID is beginning to shift, the inclusion, choices, rights and fundamental freedoms are actively championed from user groups and government initiatives. The Transforming Care agenda (Department of Health, 2012) is at the forefront of ID policy and practice, which is affecting service provision, the rhetoric and optimistically will make inroads to restoring the imbalance of power people with an ID have been historically subjected to.

### 3.2.4 Control

The seminal work of Goffman (1958) described the prevailing control by institutions as surveillance, supervision, privilege and punishment. The control was to prevent resistance and promote discipline. Illustrating that the patient becomes a product of the environment, in that the institution creates the person. This emphasises the notion of a despotic environment, where institutions control the lives of those who are there. Those who are there in relation to this research study include participants; the women and the nurses, since both were in an institution in one way or another.

The institution, as described by Goffman (1958), is the social arrangement of one rational plan that takes place under one roof, a living space insofar as it is a 'total institution.' Whilst the notion of the total institution comes from a concrete thing, the

social processes associated with it are not. In this research study the women and the nurses are facilitated to tell their story of SS, and how things happen under one roof, how this has helped them, or the opposite thereof.

Goffman's typology suggests totalising a person, which discusses the nature of a person as excluded in their own about decision making. In this research study it is relevant because decisions made about the women by the nurses are an important consideration. The women in the study were detained by virtue of the Mental Health Act, which means they are incarcerated and subject to the decision making of others.

In aligning with Goffman's theory, this research study assimilates the notion of institutionalisation and control, in the sense that the women and the nurses are to an extent the subject of block treatment, depersonalisation, social distance, and rigid routines. The nurses are placed in a position of authority over the women, to make decisions about the life of the women. The culture within the secure setting is one of surveillance, where the nurses may be seen as superior by the women and vice versa can be likened to the framework of power as described by Foucault (1982).

Control is evident in current practice by the detention of people with an ID within the remit of the Mental Health Act (1983 as amended). The essence of the Bournemouth case and subsequent Deprivation of Liberty Safeguards were a direct consequence of detention due to challenging behaviour. The facts in the Bournemouth case led the House of Lords to rule in favour of the decision to detain Mr L. However, the long running legal challenges which began in 1998 progressed from domestic to European Courts which eventually found that UK domestic law was incompatible to the human Rights of an individual. Specifically, that people with an ID do not need to be 'sectioned' as a result of challenging behaviour and/or having an ID, therefore not subject to control by the state. The implementation of the Mental Capacity Act in 2005, is an indication of a paradigm shift in policy, although it was touch and go post-Bournemouth as to whether things would change at all - had it not been for the legal advocates of Mr L things it may not have.

### 3.2.5 Reflexivity

Reflexivity in this research study is an important factor to address as it is in any research study, since this is an opportunity for the researcher to acknowledge how they have formulated the research study and contributed to the findings (Schiff, 2017). This means the researcher can assess personally held beliefs, judgements and practices during the research and reflect on how this has influenced the research.

As a researcher with over thirty years extensive experience in the field of ID, I acknowledge the importance of reflexivity in practice, and is an integral facet of the role as the researcher in this study. Qualitative research is contextual, describing the relationship between researcher and the participants can add credibility and strengthens the understanding (Dodgson, 2019). The point being - that the researcher is part of the social world being researched, and an awareness of personal characteristics and beliefs held is important to acknowledge and is of particular importance when conducting research with participants who have an ID, (McKibben, 2019). Personal characteristics for me are presented here in a sequential format- past, present and future, which is the same way the participants talked about their experiences and is presented chronologically in Chapter 6.

My past:

It has to be said that growing up for me was at a time when there was no world wide web or mobile phones – people talked to each other in person not via a screen. Being part of a big family there was a lot of talking, and I did a lot of listening. However, it was the treatment and de-valuing of others that concerned me. People with an ID were physically, socially, and culturally treated differently, these were my peers- they were laughed at and mocked. I knew this was wrong but did not know why. I decided to pursue a career to find out why this was happening and attempt to right the wrong.

My present:

In my professional life I have supported people with an ID in many settings, and more recently supporting/educating students to become Registered Nurses (Learning Disabilities). This is an important role which includes preparing students, to empower, enable and support people with an ID, as well as advocate for their rights and inclusion. I refer back to my experiences as a younger person, why were people with an ID treated differently and how can I make this better. How can I change societal and cultural perspectives to improve the lives of a marginalised group? How can I ensure society desists from this rhetoric, that those with an ID are less than the non-ID population? I focus my professional life on those concepts, although to take these issues forward personal reflexivity was involved. I realised as a nurse I could make an impact on the lives of people with an ID and the nurses who supported them, all be it small. More recently in my role as a Senior Lecturer my influence is much wider now and not just within the student LD nurse population, but amongst other academics from other fields of nursing, and Allied Health Professions.

This research:

It was important to consider my own experiences and journey from the past, present and into the future in relation to this research study. I am cognisant of the fact that I am a Registered Nurse Learning Disabilities, I am a proponent of the ID inclusion agenda however I am the researcher in this study and acutely aware of how my personal experiences and beliefs may have affected this research study. It was important to turn the lens back to myself and the effect it may have in the questions being asked, the data collected and its interpretation (Berger, 2015). As a researcher my awareness of others is controlled by unseen frames of reference and my own story has undoubtedly influenced my standpoint. Reflexivity in this research study was an iterative process and crucial to make attempts to eliminate any impact or bias within the research study.

How I mitigated biases in designing the research, recruitment to the study, data collection and analysis is presented in section 4.7.3 and highlighted in Table 9. Whereas, the chosen Methodology illustrates how the narrative approach relied on the spoken word of the participants, how they socially and constructed their world,

and told of their experiences how they see it. My view did not come into it at all, I insisted on hearing the stories from the participants, it was their narrative not mine. I transcribed the interview data and checked with the participants this was a true reflection of what they said. I kept a reflexive journal, making notes after each of the interview then discussed this in monthly meetings with supervisors.

The ethical considerations in this research study were constant from the initial idea /planning stages then throughout the study; a full discussion of Ethics is given in section 4.9. Though, from a reflexive standpoint I had to constantly revisit the strategies to keep people safe, rethink the processes and ensure everyone was indeed safe. Above all, I had to make no assumptions about my own practice and abilities; just because I am a RNLD and have been for some time does not guarantee that I can protect others. Which is why I constantly reflected on my research practices, kept a journal and discussed my progress with supervisory team.

My future:

This research study has enabled me to continue on my journey to champion the rights for people with an ID, specifically women with an ID in Secure Services. This research will influence the story I can now tell and the way I teach student nurses (learning disabilities), other student nurses, and academics across Nursing, Midwifery and Social Work. Carrying out this research will help me continue this journey to influence future policy as a reflexive and honest researcher. More importantly, to inspire future researchers who are similarly passionate, to hold their nerve, and allow people with an ID tell their stories.

### 3.3 Narrative approach

Narrative research was classically described as a method of representing an associated succession of events (Webster, 1966). More recently, it has been described as a spoken or written account given by people about people (Freshwater

and Holloway, 2010), therefore this is an extremely useful approach for this research study. Narrative research provides a thorough methodological tool to a researcher who is investigating the human experiences from a diverse group of participants. A narrative approach to collecting the data was best suited to this research as it enabled the researcher to hear from the women and the nurses first-hand about their experiences of SS. It was important to collect data using open-ended questions which is encouraged through narrative methods (see Appendix 1 interview schedule for the women, and Appendix 2 interview schedule for the nurses). Open ended questions were posed to participants, where outline topics were prepared to guide the accounts given by participants during the interview. The topics were prepared in the form of prompts to guide and focus the semi-structured interviews. In this way the approach would attempt to meet the aims and objectives of the research study.

People provide narratives or tell stories every day. Researchers from many disciplines decide on narrative inquiry since it illustrates a rounded picture of the research question (Webster and Mertova, 2007) thus helping reveal and better deal with the complexities of those issues.

Using a narrative approach in this research study enabled a participant to tell their story in their own words and for them to decide what is important about their experiences. This fits with the broad interview questions and associated topics (see appendices section for interview schedules). The participants were afforded the opportunity to talk freely, meaning the worry may become that this could mean a participant could have gone off on an alternative track. In essence this did not happen with the women, although at times the nurses did. The researcher does not find narratives but facilitates in creating the narrative (Reissman, 2008). For example, the first question posed to the women was “Can you tell me about what led you to being here?” This approach enabled the women to tell the researcher about their journey, the researcher learnt directly from the participants. A participant connects events into a sequence that is consequential for later action and for the meanings that the participant wants the listener to take away from the story. Adopting a narrative approach enabled a participant to talk about events perceived by them as important. The interviewer was listening, not interfering, yet steering the

narrative to useful repertoires that related to each question and would inform the study. These important events could then be evaluated in a meaningful way, by making sense of the narrative through analysis and description.

### 3.3.1 Narrative approach and people with intellectual disabilities

It is clear that narratives are part of our everyday life and have been part of social science studies for some time, narrative is important in many respects including freedom of speech to everyday conversations. Yet, women with an ID are a small, neglected, and devalued group, a voice needs to be given to this group (Hayes, 2007). What is also commonly known is that women (and men) with ID have been silenced, locked away and grouped into the unheard populations.

The narratives of slaves, lesbians and those with ID were classically described as, 'tales of the outcast, the marginal and the silenced' (Plummer, 2001a, p. 91). However, there has been a level of criticism in relation to research 'with' people with ID in terms of participating in research (Bogden and Taylor, 1976). In the contemporary sense, researchers and academics have learned from earlier narrative research approaches with people who have an ID to the point that there is now a sense within the literature to suggest that people with ID have important stories to tell and can, with appropriate support, take part in research as collaborators and narrators (Björnsdóttir *et al.*, 2014). Furthermore, the recent moves to adopt more participatory approaches in research indicate that people with ID make an invaluable contribution. Some researchers further this by saying that research should be more than participatory and should be emancipatory in nature. However, people with ID are now being seen as the experts in their experiences and not the subjects of 'our' research (Knox *et al.*, 2000; Northway, 2000). The fact remains in this research study that the women were currently in locked units or talking about when they were in locked units previously. This aim in this research study is to explore the experiences of women with an ID in those locked units and how the nurses supported those women, in such complex situations. This is a unique facet to this research study and can contribute to the field of women with an ID in Secure Services. It provides a significant dimension to methodological approaches used in

research of this nature, in that security was an important consideration and discussion in the power relationships of participants.

A cautionary tale was presented by Björnsdóttir *et al.*, (2014), who alerted researchers of the concern that people with ID in narrative inquiry have been labelled by medicine, education and social systems as incompetent and childlike, and will have had a trajectory of discrimination, exclusion and marginalization. Furthermore, Pierre Bourdieu's invitation to *réflexivité* (Bourdieu and Wacquant, 1992, p. 72), asked researchers to consider their presuppositions and how their cultural and social background influences their interpretation of the social world. Although, the juxtaposition is classically presented in Wolfensberger's Social Role Valorisation model (Wolfensberger, 1983), and O'Brien's (1987) 5 Accomplishments. The agenda was inclusion and to speak up for people with ID. This has been reaffirmed more recently in The Valuing People initiatives (2001: 2009) with a contemporary viewpoint illustrating that people with ID have a voice, should be included and can speak out for themselves for independence, rights choices and freedoms, as well as having the ability to challenge a disabling society.

The individual accounts given by each participant in this research allowed them to tell their own story, within their personal, social, and cultural context. This meant that this researcher heard about experiences of SS from the women and the nurses who are in, or who have experienced, such settings. Women with an ID were able to talk about experiences from their own perspective, in the context of a personal journey. Conversely, the nurses were able to share their experiences from a professional angle, which is undoubtedly different to the views held by the women. This was achieved by asking the nurses the question 'how do you support women with an intellectual disability in secure services?'. Thus, this enabled all the participants to talk freely and speak candidly about their experiences of SS. This is particularly important since the women with an ID in SS need support and a process of facilitation to speak about their experience. This will contribute to the body of knowledge insofar as there is a dearth of literature where perceptions of the 'voice' of women with an ID is absent. This is important as some of the participants will be women with an ID. With this in mind, taking part in the research may have allowed



participants to have a positive experience in the sense of being listened to, and a feeling of being valued as contributors to the research study.

What has been shown by presenting the overarching philosophy and theoretical framework are the complexities and associated tensions in carrying out a research study with women who have an ID and have experienced SS.

### 3.5 Chapter summary

This chapter has provided the reader with the methodological approach adopted in the research study by giving an account of the underpinning philosophical and theoretical standpoints. It has explored the conceptual framework and how the adopted framework is appropriate to this research study. Thus, it has illustrated the importance of social constructivism and how the ontological and epistemological standpoints were relevant to this research study. The chapter has examined and critiqued the researcher's dual role as practitioner/researcher. Finally, this chapter has illustrated why thematic analysis was appropriate in the research study.

## Chapter 4: The method

### 4.1 Research design

The research design adopted for this study was one of in-depth exploratory qualitative research since the principal question relates to the life experiences and behaviour of people (Silverman, 2013). The best way to do this was to talk to those that had experienced SS, and a narrative approach enabled this through the medium of semi-structured interviews. Narrative inquiry is a subtype of qualitative research, centring on life experiences as narrated by those that live them (Chase, 2008). This provided the method to generate data in words, and thus facilitated an opportunity to hear from the women and the nurses about their lived experience and perspectives of SS.

### 4.2. Sampling

#### **Research site selection**

To answer the research question, it was necessary to gain access to research sites which could provide potential research participants. In order to do this, there were characteristics required of a research site. First, the site had to be currently providing secure inpatient services for women with an ID. Or secondly, the site had to have provided secure inpatient female ID services in the past fifteen years. This was decided as an inclusion criterion to give the research study a contemporary style as opposed to a historical approach looking into services from decades ago. Finally, the sites must have employed registered nurses (learning disabilities or mental health) who are currently working or have previously worked within those services.

Part of the literature search conducted in Chapter 2 identified failings and systematic abuse taking place in services for people with ID. The response to the failings within the services was the Stephen Bubb report (Winterbourne View -Time for Change,

2014) and subsequent implementation of the Transforming Care Agenda. This shift in policy was influential in changing the direction of in-patient services. In practice this means people with ID that do no longer require hospitalisation are being repatriated to the community. These services are being planned and provided within the community by public, third sector, private and voluntary organisations. This affected the selection of research sites in this research study since there were organisations currently offering, and planning to offer, in-patient female secure ID services, as well as non-secure services and community accommodation including living in their own home. Because this is a relatively new way of service provision the researcher decided to retain the scoping of possible research sites within the NHS, on the basis that the NHS is a well-established public-funded organisation, engaged in research and actively promoting patient and staff participation in research studies, as set out in the NHS Constitution (2012). Additionally, public bodies protect participants who are involved in research within the remit of the Mental Capacity Act 2005 (gov.uk). In essence this meant that research study sites were found via National Health Service (NHS) internet sites. Two sites were found via the Integrated Research Application System (IRAS) and Health Research Authority (HRA), and the researcher was then able to apply to each area via the online portal. This created an electronic request to both potential sites and each site then accepted the request to be a research study site. Both research sites were located within the northern region, the same location as the researcher. This meant those research sites happened to be easily accessible and known to the researcher. Research sites will hereafter be referred to as Site A and Site B.

Site A is currently providing in-patient female ID secure services and employing registered nurses (learning disabilities and mental health) working within those services. Site B previously provided in-patient female ID secure services and currently employs registered nurses (learning disabilities and mental health) who have worked in female secure ID services. Through implementing the Transforming Care Agenda, Site B was actively supporting the return to community living for the women, following the closure of the women's in-patient secure services. This ongoing support was provided through the community transition teams (CTT) and secure outreach treatment teams (SOTT). In principle this meant Site B could

potentially know of women with an ID who had experienced secure services and could be a potential participant.

### **Participant sampling**

Non-representative sampling was used in the study, specifically availability and convenience sampling, which is commonly adopted in nursing research (Maltby *et al.*, 2010). Non-probability sampling was used to ensure that participants had the experiences and attributes that would be likely to yield rich data to answer the research question (Hunt and Lathlean, 2015). Whilst this approach may have introduced a sampling bias in that participants were from the North East of England, as opposed to elsewhere in the world. The research sites provided Secure Services for women with an ID and Registered Nurses on the Nursing and Midwifery Council, Learning Disabilities and Mental Health parts. The research sites were amongst the largest providers of ID services in England, although known to the researcher as a provider of student nurse placements this issue was acknowledged within the exclusion criteria, which stipulated student nurses could not participate in the research. Additionally, because of the way services are organised, the women in the study were from various locations across England, not exclusively from the northern region. The nature of SS is that patients who reside in these establishments come from much wider catchment areas of the UK.

#### **4.2.1 Inclusion and exclusion criteria for the women and the nurses**

Inclusion and exclusion criteria are generally used with sample sizes in order to obtain rich in-depth data (Taylor, 2014). In order to recruit appropriate women and nurses a strict set of inclusion and exclusion criteria were applied in this study and shown in tables 2 and 3 below.

**Table 2: Inclusion and exclusion criteria for the women**

Inclusion criteria	Exclusion criteria
Working age (18-65) adult women with an ID	A man who has an ID
Women with ID who are experiencing secure	A woman who has an ID who is experiencing a

services.  Women with ID who have experienced secure services in the past.  A woman with ID and has capacity to consent to participate	mental health crisis.  A woman with an ID who is on probation.
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**Table 3: Inclusion and exclusion criteria for the nurses**

Inclusion criteria	Exclusion criteria
Registered nurse (learning disabilities)  Registered nurse (mental health)  Those RNs who are currently supporting women with ID in secure services  Registered nurses who have previously supported women with an ID in secure services	Registered nurse (child)  Registered nurse (adult)  Non-Registered care staff  Family members, advocates, or student nurses  RNs who have no experience of supporting women with ID in a secure service

Therefore, the participants in this study included women with an ID who have experienced or are currently experiencing secure female services and the registered nurses (learning disabilities or mental health) who are currently or have previously supported this population.

#### 4.2.2 Sample size

Whilst there are no precise regulations in relation to a study sample size, six to ten has been suggested as a starting point (Moule and Goodman, 2013). Research conducted with people with intellectual disabilities (ID) was carried out by Nicholson *et al.*, (2013) with a target of twelve participants and an actual recruitment of ten. Nicholson *et al.*, (2013) give guidance and recommendations for conducting research with people with ID. The target number for recruitment for this research study was twenty-four participants in total. Twenty-four was decided because this would include twelve participants who were women with ID and had experience of SS and twelve who were registered nurses working in SS. Within that, participants would be recruited from Site A and Site B. There would then be two groups from

each site, namely the women and the nurses. Thus, the availability and convenience target sampling consisted of:

- Twelve participants who were women with an ID and have/had experienced secure services: six from study site A and six from study site B
- Twelve registered nurses who support women or have supported women with ID in secure services: six from study site A and six from study site B

Therefore, the target sample was twenty-four participants, which included twelve women and twelve nurses. In reality there were nine semi-structured interviews carried out with the women, and twelve with the nurses, meaning a total of twenty-one interviews were conducted. One of the women withdrew afterwards which is discussed later in this chapter. This meant there was a total of twenty interviews for data analysis.

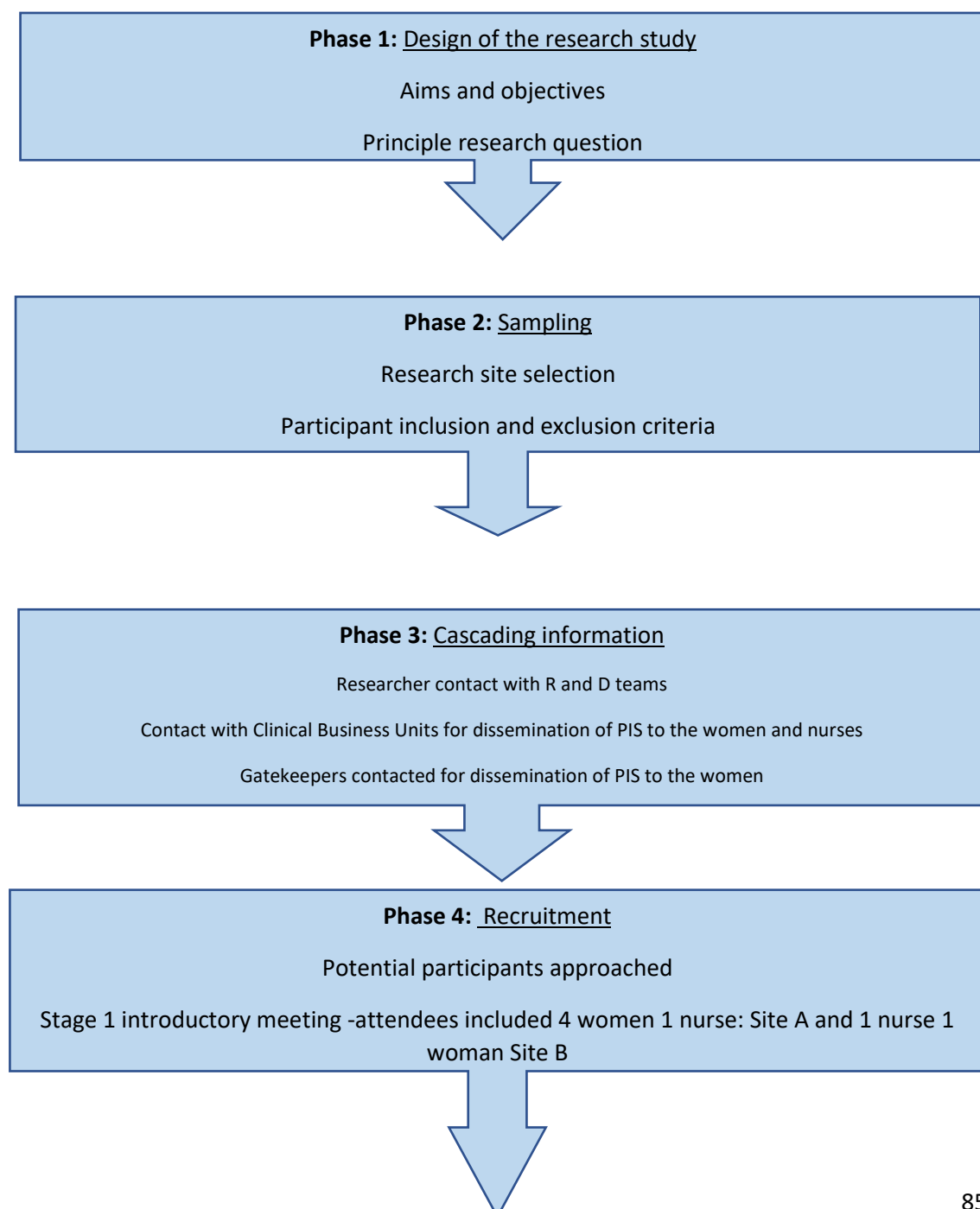
### 4.3 Recruitment

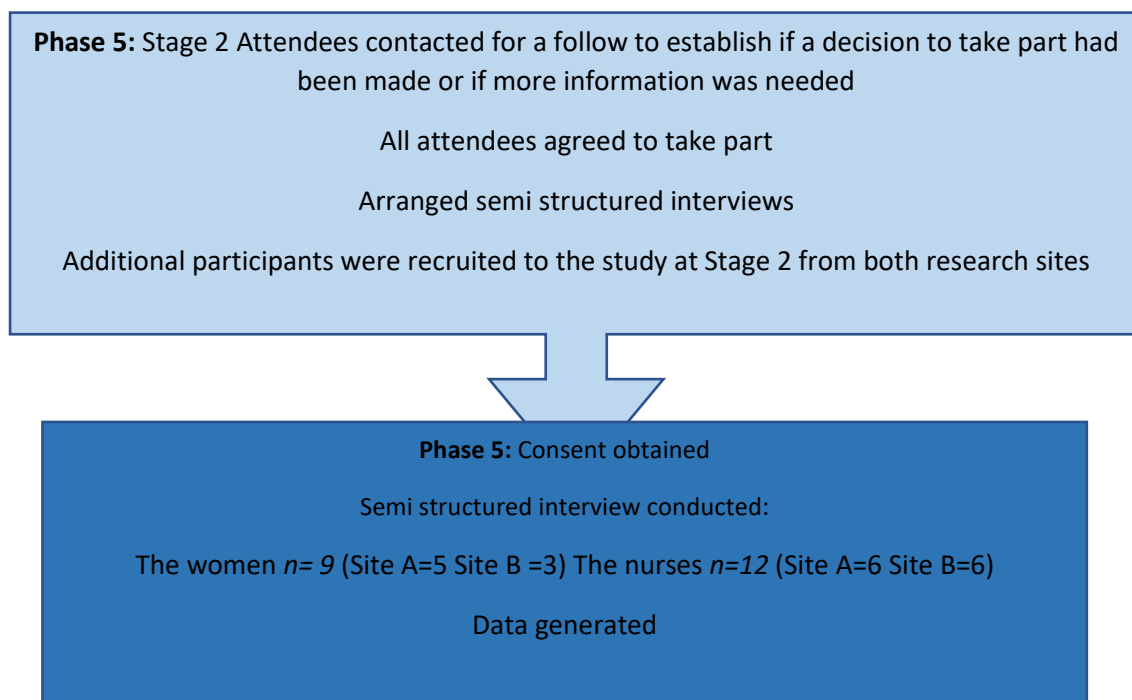
The recruitment strategy in the research study included conducting a series of meetings at Site A and Site B, where details of the method, aims and objectives of the research study were presented. This enabled identified personnel, nominated by the Trust Research and Development Department, in each study site to receive all the information about the research study, to ask further questions and agree with the researcher a process for cascading the information within their areas. The identified personnel were asked to identify areas where there were individuals known to them who would be likely to match the inclusion and exclusion criteria for recruiting both the women and the nurses. A process was followed, which is described in detail and shown in Appendix 13, in order to reach any potential eligible participant (nurse or woman) in a way that meant no-one was ignored and all areas were explored to reach anyone that may be eligible to take part. Some clinical areas could have generated more than one potential nurse or woman participant. The inclusive approach is further discussed in the ethics section. The researcher did not approach any potential participant directly as it was more appropriate for potential participants

to be approached by people known to them. This is also discussed further in the ethics section.

The overall approach to recruitment consisted of five central phases. Each phase involved a systematic approach to recruiting participants from both study sites. Figure 3 shows the phases followed in the research study to recruit participants.

**Figure 3: Flow chart showing phases in the recruitment of participants**





Once eligibility was confirmed and/or a potential participant would like to know more about the research, they were contacted and invited to an introductory meeting which was open to the women and the nurses together. Nicholson *et al.*, (2012) discuss the benefits of meeting potential participants when conducting research within ID services on an informal basis and prior to recruitment. It was felt that talking to women and nurses openly in each other's presence would help to dispel any fears or suspicions about the purpose of the research and begin the process of establishing trust. Establishing trust is further discussed in the ethics section.

Recruiting participants from Site A was organised through the Research and Development Leads within the Trust. Cascading information to clinical team meetings by sharing the participant information sheets (PISs), then identifying further forums that could be approached in order to discuss the research. This included managers meetings and a fortnightly patient forum (females). This was to identify any potential participants who clinicians thought would meet the inclusion criteria and may like to know more about the study. This process lasted several weeks until



individuals were identified by someone known to them and were able to be approached by the researcher.

Recruiting participants from Site B was not as straightforward or as timely as Site A. This was anticipated due to the closure of the female in-patient SS, and subsequent resettlement of the women into community living. The Research and Development Leads cascaded information about the research study to the clinical business units (CBU). Members of this forum shared information with managers who then contacted the researcher. Introductory meetings were held at several locations, including the office base of the community liaison teams and the manager's office in a supported living scheme.

At the introductory meeting, the PISs were distributed. There were three PISs for the study: one for the women, a second for the nurses and a third accessible version which are all provided in the Appendices section and numbered 5, 4 and 3 respectively. The researcher gave a verbal overview of the research study by going through the PIS, explaining how the research study will be conducted and what participant involvement would be for the nurses and the women. All questions were answered, and the interview process and potential interview questions were discussed. Attendees were encouraged to think about whether they would like to participate for a minimum of two weeks and were not required to decide at the time.

After the introductory meeting, a minimum period of two weeks was given. This was to allow time for a potential participant to think about the research, what their expectations were about the research and what involvement would mean to them. Some participants needed a longer period of time, for example where the nurses were on annual leave for two weeks.

#### 4.3.1 The women

This two-week cooling-off period meant the women could discuss any implications of their involvement in the research study with professionals or others, for example advocates, carers, friends, and family. This period of time also enabled the women to think and decide about whether they wanted to participate or not. This was important in that the women were able to process the information, weigh up any involvement, and consider what it would mean to them. Crucially, the women were able to understand that participation in this research study was different from an intervention and had different purposes and timescales. Meeting the women at this stage enabled the researcher to facilitate introductions, talk to the women about the research and show the women that the research would not be harmful. The beginnings of a trusting relationship began here, yet this was not evident until the next stage.

The researcher followed up the women who had attended an introductory meeting with a range of approaches that were specific to their individual circumstances. This meant the researcher returned to the ward to meet the women at a time best suited to their sessions and appointments. The purpose of this follow up was to establish if they had reached a decision about whether to participate or if they had any further questions about the research study. Four women attended the introductory meeting, and all decided to participate in the study. The women who were living in the community were followed up with a telephone call.

#### 4.3.2 The nurses

For the nurses participating in the research, this may have an impact on their colleagues, for example working around the ward duty rota since meetings scheduled to take place whilst on duty would undoubtedly affect the other nurses on duty at that time. The nurses were followed up by a telephone call to their place of work or an electronic message sent to their NHS email address.

### 4.3.3 Consent

Consent to take part in the research study was addressed before the interview took place. This was determined by presenting the participant with a copy of the consent form, reading it aloud then inviting participants to ask questions. A blank copy of the consent form is provided as Appendix 6 in the Appendices section. At this stage potential participants were asked to acknowledge that they agreed to take part in the research by signing the consent form or by giving verbal assent.

Once a participant agreed to take part, they were given a consent form. The researcher read through the contents of the form and gave participants the choice of signing the consent form or giving verbal assent. All the nurses and six of the women signed the consent form. The hard copies were later uploaded to a secure university hard drive and the originals shredded. Where verbal consent was given, this was re-affirmed when the recordings began. The recording device was security encrypted and a strict set of guidance was in place to protect the recordings once they were made. This entailed signing in the device on entry to the wards with the on-site security control room staff. Next, a further strict set of criteria was adhered to on leaving the ward or area which was to store the device as securely as possible during transit, and not on display and locked in the boot of the car. The recordings were then immediately transferred onto a university U drive. Subsequently, the original recording on the portable device was deleted.

## 4.4 Semi-structured interviews

Semi-structured interviews were used to elicit narratives from the participants to produce in-depth qualitative data. The rationale for adopting a narrative approach is discussed earlier in this chapter and in further detail in the methodology chapter. This chapter will outline the procedural detail of how the semi-structured interviews were operationalised. Unstructured interviews would have been very challenging without any agenda, and a fully structured interview would have been too restrictive.

Semi-structured interviews were the chosen method because this approach can be an interaction and a relationship at the same time (Maltby *et al.*, 2010). Semi-structured interviews as a research method have been compared to natural conversation since there is an authentic relationship between interviewer and participant (Maltby *et al.*, 2010). This was particularly important within the context of conducting research with participants who have intellectual disabilities (ID). Adopting semi-structured interviews allowed the researcher to take a flexible approach with each participant. This was because it was seen as important to be mindful of the need to have an authentic relationship with participants who had an ID and appreciate the importance of creating and sustaining a conversation.

In this study, the researcher acknowledged the responsibility to conduct the interviews with skill and the need to demonstrate rigour in the interviewing process. To ensure this, the Ten Interview Principles and Skills were applied, as set out by Patton (2014). These are to ask open ended questions, be clear, listen, probe as appropriate, observe, be both empathetic and neutral, make transitions, distinguish types of questions, be prepared for the unexpected and be present throughout. It is common for narrative researchers to use fewer questions in the interviews, typically starting with an open-ended question (Freshwater and Holloway, 2015) whilst keeping the questions as straightforward as possible. The questions asked during the semi-structured interviews were designed to capture the detail from all participants in a way that enabled them to tell their story as they saw it in their own words. Because the research was exploring experiences of women with ID and the nurses who support those women, distinct yet similar questions had to be prepared in such a way that both the women and the nurses could give a rich and detailed account and talk to the researcher about their experiences. In view of this the researcher prepared two separate interview schedules: one for the women and another for the nurses. Having the interview schedules in readiness meant that the researcher was prepared, enabled the researcher to maximise the time during each interview and centred the interview around the research study. This is supported by Maltby *et al.*, (2010), who recommended that the interviewer needs to be active, responsive, and flexible.

The interview schedules consisted of open-ended questions and topics within each question. There were five general questions asked of the women and three of the nurses. Both interview schedules are provided in the Appendices section (Appendix 1 for the women and Appendix 2 for the nurses). Although there could be some degree of flexibility in the order of asking questions during each interview, in actuality the order did follow the interview schedules.

The semi-structured interviews were conducted in a range of settings, all private areas such as established quiet/private rooms, the ward manager's office, the day room, the sensory room or the participant's own home. The aim was to secure a space which was quiet without distractions. However, at times this was impossible to achieve. Strategies used to preserve the protected time and privacy of participants included attaching a note to the door requesting privacy and no interruptions. Since most doors had transparent sections, this meant anyone entering the ward could see into the rooms. As such, it was important to indicate that a meeting was in progress but specifically not identify research was taking place, as this would breach the confidentiality of a participant.

#### 4.4.1 Semi-structured interviews – participants with intellectual disabilities

It is acknowledged that conducting interviews in research elicits people's views and perspectives on the world. Methodological challenges faced by a researcher when participants have an ID has been the subject of discussion amongst researchers and academics. Lewis (2002; 2004) report on the methodological challenge of interviewing people with ID and the issue was further discussed by Lewis and Porter (2004) who said that participants with ID need to trust that they will be listened to, responded to and understood, or in essence that their views are valid. Whereas Nind (2008) noted the social and historical context as a methodological challenge, in that participants with ID need to have self-esteem to believe their views are valid and important. This was supported by Northway (2014) who advocated for inclusion of people with ID in research and guided researchers to ensure participation is not

harmful and has benefit. Historically people with ID have been silenced and excluded from research or involved without giving consent. Lewis (2002; 2004) asserted three key principles to consider when conducting semi-structured interviews with people who have ID. These are that the interviews are authentic, and views are expressed as fair and representative, and that validity/credibility are maintained, requiring checks as to whether interpretation of views expressed are correct. Similarly, it is suggested that reliability/trustworthiness are maintained, in the sense that responses should be representative of what the person believes.

Narrative inquiry through semi-structured interviewing is centred around an interest in life experiences, as recounted by the people that live them (Chase, 2008). The women in this research study were facilitated by the researcher to provide an account of their journey, to talk about their typical day and talk about the support and relationships at that time in their current experience of SS. The semi-structured interviews also enabled the women to talk about their past experiences of SS, allowing them to give an account of what their experience of SS is, or what their experience was in the past.

Although there is evidence in the literature to guide researchers when conducting interviews with participants who have an ID, there is no rule book since people with ID are not a standardised group. Broad recommendation include a genuine style of interviewing, building up trust over time, probing/questions, and a natural style of interviewing, all of which can form the basis of shared narrative based on a 'natural exchange' (Goodley, 1998; Lewis and Porter, 2004).

Therefore, conducting research with participants who have an ID is not straightforward and needs careful planning and consideration. There are strategies and communication aids known as augmented and alternative communication (AAC) available to assist researchers when participants have profound and multiple IDs (Cambridge and Foster-Jones, 2003). The review of the literature suggested to the researcher that the population of women in secure ID services would be more likely

to have a mild or borderline ID. Having a mild or borderline ID means that the women would be more able in the respect of being able to speak up for themselves, and this meant that AAC would most likely not be needed.

#### 4.4.2 Participants with an intellectual disability and the presence of a learning difficulty

Having an ID does mean different things to different people, and the Diagnostic Statistical Manual of Mental Disorders: Fifth Edition (DSM-V) now provides a definition with less emphasis on the level of IQ (as was the previous standard for diagnosis), and instead centres on the ability of the person in relation to personal, social, and practical activities associated with daily living. The women participants in this research study had a mild ID, meaning that they would have an IQ between 50 to 70, be slower than typical in all developmental areas, be able to learn practical life skills, be able to attain reading and math skills up to grade levels 3 to 6, be able to blend in socially and could function with daily life. About 85 percent of people with ID fall into the mild category and many even achieve academic success (Gluck, 2014). Furthermore, there may be a presence of a learning difficulty in the form of dyslexia or dyspraxia, meaning that the researcher needed to consider and implement additional learning support requirements for such participants.

In view of the likelihood of a learning difficulty being present, the researcher prepared a third PIS in accessible version (see appendix 3), in a format that could be understood by a potential participant who had a learning difficulty. Potential participants could inform the researcher of any additional support requirements in the introductory meeting. That said, no-one at that first meeting disclosed any learning difficulty or that any additional support was needed.

As a result of snowball recruitment women from harder to reach areas were contacted as potential participants, which included women that had previously experienced secure ID services and were now living in the community. An individual introductory meeting was held with those women ( $n=3$ ), during which one of the

women disclosed having dyslexia. This meant the researcher was able to verify what specific needs were required, as dyslexia can present in many forms and there are many different requirements. Dyslexia can mean many different things to many different people. The participant confirmed that certain things would be beneficial to her specifically.

- Left aligned text with a plain evenly spaced font in black ink
- Coloured paper (she suggested pink or green)
- Thick paper so you couldn't see through it
- Paper with a matt finish is best for reading as opposed gloss
- Shorter sentences in the text, which are direct and concise

These adjustments were made for the semi-structured interview and at the subsequent meeting of going through the transcription.

#### 4.4.3 Interviewing the women

The literature supports the need to involve people with ID in research (Swaine *et al.*, 2011; Tuffrey-Wijne *et al.*, 2011; Brooker *et al.*, 2014). This is furthered developed by Cook and Inglis (2012), who provide strategies for participation and inclusion in research studies when carried out with men who have an ID from SS. However, there is a limited evidence base on conducting semi-structured interviews with staff present (Morgan *et al.*, 2013). Those limited studies identified that a person present could be a third party, a proxy, a supporter, an advocate, family member or unpaid carer. Cummins (2002) stated that a proxy or supporter may need to be present, yet Clegg (2003) proposed that, where supporters are present, they are allowed a separate opportunity to communicate views of their own. The presence of a third-party during interviews in this research study will now be discussed.

##### 4.4.3.1 Interviews with the women and a third party/parties present

Traditionally interviews are conducted on a one-to-one basis between the interviewer and participant, however the presence of a third party is often dictated when conducting research with participants who have an ID. This facet to collecting the



data was factored in at the research design stage, accepting it as an integral aspect of conducting interviews with the women. The women were required to have a staff member(s) present during the semi-structured interview for three reasons. Firstly, the legal justification associated with their treatment, care or detention under the remit of the Mental Health Act (1983 as amended). In practice this means the women could be subject to continual or intermittent observations, therefore a member of staff would need to be with them constantly or observe them at specified intervals, for example every fifteen or thirty minutes. Secondly, the safety of the participant was an issue since the researcher was a stranger to them and was conducting an interview which may cause distress (managing distress is discussed in detail below). Thirdly, the safety of the researcher spending time in a secure unit was considered in the same way it would be for any visitor to the unit. Specifically, it was a requirement to not be left alone with the women and issued with an alarm. Those present were all known to the women and included Registered Nurses Learning Disabilities (RNLD), Health Care Assistants (HCA), Community Learning Disability Nurse (CLDN) or a Home Leader. A further discussion of semi-structured interviews with staff present is presented in the reliability and validity section 4.7, and further methodological implications are considered in section 6.2. Table 4 below identifies the staff present during the semi-structured interviews with the women.

**Table 4: Staff present during interviews with the women**

	Location of semi-structured interview	Registered nurse present	First health care assistant present	Second health care assistant present	Home leader present
P12	The ward- Site A	✓	✓	✓	
P13	The ward- Site A		✓		
P15	The ward- Site A		✓		
P16	The ward- Site A		✓	✓	
P17	The ward-		✓		

	Site A				
P18	Step down service- Site B	✓	✓	✓	
P19	Own home	✓			
P20	Own home				✓

#### *4.4.3.2 The interview process*

An additional layer of explanation was performed at the beginning of the interview where a third party was present, taking further time to explain to the women and the third party/parties about the research study, helping to make everyone comfortable and explain what was about to happen. Confidentiality was addressed at this stage. Participants were reminded of the information in the PIS in relation to confidentiality. Specifically, if they named an individual person or service then this would be anonymised in the transcription. Further, it was also reiterated that if anyone felt uncomfortable the interview would be terminated. The third-party/parties present were also included in the explanation about confidentiality at this point, namely that anything the women would say during the interview was confidential and they were reminded about possible breach of confidentiality, which all third parties agreed to. Moreover, the third parties were informed about the possibility of disclosure during the interview, as a participant could disclose an issue to the researcher of an issue that may need to be reported.

During the interviews, the women included the person present in their narrative, referring to historical and momentous events and almost bringing the staff into the interview. At times, the women asked the staff for corroboration of dates, names of staff, other wards, and hospitals. This aspect of collecting data is considered further in section 6.2.

#### *4.4.3.3 Managing distress*

Because the staff present were known to the women, they would be aware of any signs or triggers that were present if the participant became distressed. This meant that if a participant did become distressed the person who knows them could alert the researcher immediately, and then the interview would be terminated. In a further attempt to minimise and manage any potential distress there were strategies put in place to keep participants safe, and a procedure on what to do was created. This was accepted by the research ethics committee (REC) as a way of dealing with potential psychological distress to participants during their contribution in the research study. Strategies to minimise and manage distress of any participant involved identifying a potential risk at the outset, recognising what the risk is and then implementing strategies to minimise that risk. A table illustrating how this was planned and what the strategies were is provided in Appendix 12. Managing distress is also addressed further in the ethics section at the end of this chapter.

#### *4.4.3.4 A blended approach*

Dyadic interviewing was introduced as an approach by Morgan *et al.*, (2013). They highlighted that the presence of another person other than the participant with an ID could create a dyadic interview approach, where the dyad is the participant, the researcher and a key support person known to the participant. Some researchers position this as triangulation, whereas Caldwell (2014) presents the approach as a way which can facilitate and empower a participant by giving choice and self-determination. Also, triadic interviewing includes an interviewer, interviewee and a significant other, which is a typical approach usually found in paediatrics (Cahill, 2007). Joint interviewing was presented as an important aspect of collecting in-depth qualitative data, where the dyad was a married couple being interviewed on the distressing subject of life-limiting illness (Morris, 2001). The researchers in that study noted that the data was not originated from an individual interview or a focus group. Cummins and Masters (2002) state that seeking the views of a proxy has been adopted to thwart the methodological challenges faced by researchers when conducting research with participants who have an ID. A third party was present in research conducted by Cook and Inglis (2012), which involved men with an ID who were in a secure service. What is noteworthy about that study is the third party was a

co-researcher/employee of the organisation and known to the participants. Nevertheless, any contribution from the third party was not discussed or noted in the findings.

It is crucial in any research to adopt an approach that will generate data which is rich enough to meet the aims and objectives of the study (Seymour *et al.*, 1995). Guidance for researchers when conducting interviews with participants who have an ID was set out by Goodley (1998). In reality, the approach adopted in this research study to conduct the semi-structured interviews with the women and another person(s) present was a hybrid of the above options. In that, this study cannot be labelled as being dyadic, triadic, individual interview, joint interview or focus group. Nor can this study be described as having a proxy, supporter, or family member present. The researcher is presenting a hybrid of current definitions and possibilities of attendees when participants have an ID and by necessity have a significant other present. This push will embrace the current impetus to engage and recruit participants with an ID, as well as forwarding the opportunity that such participants can contribute to service provision that will benefit themselves and their peers. However, this should not be to the cost of being so novel or indeed maverick that this hybrid approach is discounted. The intention here is to provide a tool for researchers with a unique and novel methodological approach to involving participants with ID and significant person(s) who are attending with them.

The preamble to the semi-structured interview was given to the women at the outset and can be seen in the interview schedule (the women) as Appendix 2. This was to give the relevant information the women needed in order to continue in a way they could understand. It began with an introduction for participants about how the semi-structured interview would be conducted. At this point, participants were informed about the confidential aspect of the semi-structured interview. As such, should any names, places or details of any living person be mentioned during the semi-structured interview, this would be disguised, and no identifiers would be evident. An explanation was given as to what would happen once the semi-structured interview had taken place. In essence, this was to have all the audio recorded data transcribed

into one document for each participant. Consent (as discussed earlier in this chapter) was addressed at this stage and the recording device was switched on before proceeding to the interview. Where a third party was present the researcher included them in the interview (see interview schedule as Appendix 1). The researcher explained the process of the semi-structured interview to the participant and staff present, going through the process and reminding everyone of confidentiality and ending with the option for anyone to leave. A caveat was put in place to reiterate the points from the PIS that if anyone was uncomfortable, in distress or had any issue which hindered their presence during the interview, they needed to alert the researcher immediately and the interview would be terminated at once.

The five questions (see Appendix 1) posed to the women were:

1. Can you tell me about what led you to being here?
2. What is your experience of female secure services?
3. Can you talk me through a typical day?
4. Where are your best relationships?
5. Where do you get most support?

The semi-structured interviews carried out with the women all took place in the secure ward or their own home. Interview duration times varied, and table 5 below sets out where the interview was conducted and the length of time the interview lasted with the women. The shortest interview lasted eighteen minutes and the longest was forty minutes. The average interview duration was thirty minutes.

**Table 5: Interview duration times with the women (n=8)**

Participant number	Research site	Interviewed	Interview duration time in minutes
P12	A	Ward	20
P13	A	Ward	18

P15	A	Ward	40
P16	A	Ward	25
P17	A	Ward	30
P18	B	Step down service	38
P19	B	Own home	31
P20	B	Own home	35

#### *4.4.3.5 Semi-structured interviews - the women who are currently experiencing secure services.*

The women currently experiencing secure female ID services were residing in services at research study site A. In practice, this meant that recruited women currently in SS could only be interviewed in the premises of study site A. The reason for this is because the women are in SS and detained within the remit of the Mental Health Act (1983 as amended). The literature supports this position as discussed in Chapter 2, where it is outlined and accepted that the women in secure services are detained by virtue of assessment, treatment, criminal and/or challenging behaviour. Undeniably the women have encountered the criminal justice system (CJS) and are in security as a result. The literature furthers this by positioning the women in secure services for treatment and as patients who are in receipt of detention, observation and restrictive practice placed upon them.

It was anticipated by the researcher that some of the women would have un/escorted leave in and outside the grounds of site A, where the semi-structured interviews could have been conducted. The researcher felt that this was independent and private time for the women and was respectful of this. On this basis the researcher chose to be courteous of the women's limited independence and conducted the interviews in the secure service, therefore not encroaching on the women's privacy.

In view of the constraints placed upon the women currently in SS, the researcher was acutely aware of the fact that the semi-structured interviews would need careful consideration. This included the possibility that the interviews with these women would vary depending upon their unique circumstances and would be high risk. The potential risks were addressed (see Appendix 11 strategies to minimise risk).

The semi-structured interviews with the women in the wards had to occur in various formats, because of the legalities in place associated with their detainment under the MHA. This included one-to-one (researcher and participant) one-to-two (researcher, participant, and staff member present), one-to-three (researcher, participant and two staff members present) and one-to-four (researcher, participant and three staff members present). The intricacies of this arrangement are discussed further below.

#### *4.4.3.6 Semi-structured interviews - the women who have previously experienced secure services*

Due to the transforming care agenda, services were under closure and this meant that some of the potential participants were living in the community or awaiting transition to a community residence. Participants who were women with an ID and had previously experienced SS had done so within Site B. As discussed earlier in this chapter the provision of inpatient female secure service at Site B had closed a number of years ago. It was anticipated that these women would be harder to reach since the service had closed and support was independent of the NHS. The women were now in community-independent living or awaiting resettlement to the community. This meant the semi-structured interviews with these women had to be arranged differently from those who were currently in SS. There were two groups for consideration: women living in the community and those awaiting discharge.

#### *4.4.3.7 The women living in the community.*

Interviews with the women who had previously experienced SS from Site B, and were now living in the community, were conducted in their own home. Those women were currently being assisted to live independently with support workers. The

support was provided through a private independent organisation. This was the case for P19 and P20 ( $n=2$ ). As well as support staff, health care support was provided by an NHS Community Learning Disability Nurse (CLDN).

The researcher arranged the interviews by liaising with the CLDN and home manager for an appropriate time when the participant and the CLDN/Manager were available. Both participants invited the researcher into their home and engaged with the interview. Conducting a research study and the presence of a third-party during the interview is discussed in section 4.4.3.1 and 6.2.

#### *4.4.3.8 The women waiting to be discharged to community.*

Due to the Transforming Care agenda and subsequent closure of various female in-patient SSs, it was anticipated that some participants would be in a transition phase, meaning they were preparing to be discharged from hospital to community living. There was a step-down service located at Site B where one woman was living alone, and discharge was imminent. The woman (P18) consented to participate, the interview took place in the step-down service located in study site B, and there were three staff members present (one RNLD and two HCAs). As noted above conducting research with a third-party present is discussed section 4.4.3.1.

#### *4.4.3.9 Semi-structured interviews and participants who were registered nurses - the nurses.*

Participants who were registered nurses, the nurses, were all registered nurse learning disabilities (RNLD), and were offered an option to be interviewed on campus or at a location within their NHS trust. The aim of offering the nurses the opportunity to come on campus was to provide a neutral environment away from their usual duties which could enable less distractions. This issue is considered further in the discussion in the reducing bias section of this chapter. All the nurses decided to be interviewed within their working environment. In the case of nurses working on the ward the interview took place in the office or nurses' station. For the community



nurses, the interviews were conducted in a base location regularly accessed by them.

The semi-structured interviews conducted with the nurses were different from those conducted with the women. The nurses were asked three questions, which were:

1. How do you support women with an ID?
2. How prepared and trained do you feel to engage and support women with an ID?
3. How do you feel you might develop this approach both in the short and long term?

The questions were designed to meet the overall aims and objectives of the research. Moreover, the nurses were able to tell their story about how they support a woman with an ID in SS. In addition, information on the preparation of the RNs, along with their practice, assumptions, and experiences, were secured through the narrative process. The intention here was to listen and avoid asking too many questions of participants.

The semi-structured interviews carried out with the nurses all took place in their usual working environment, which included the secure ward, their office or in the case of community transition nurses the interview took place in the ward they are transitioning patients from. Table 6 below shows the duration of the interviews with the nurses. The shortest interview lasted twenty minutes and the longest was sixty minutes in duration. The average interview time was forty-two minutes.

**Table 6: Interview duration times with the nurses (n=12)**

Participant number	Interview duration time in minutes
P1	60
P2	35
P3	37
P4	20

P5	37
P6	30
P7	40
P8	60
P9	55
P10	58
P11	34
P14	30

#### *4.4.3.7 Attitudes of participants*

The attitudes of the participants towards the researcher varied at different stages in the study. At the recruitment stage and introductory meetings there was a sense of apprehension and doubt, which was anticipated to some extent and factored into the design of the study. For example, this included the decision to wait up to two weeks after the introductory meeting before obtaining consent to the semi-structured interview.

The participants showed interest to learn more, and once consent was given, and the interviews began there was a sense of relaxation from the participants. This was noticeable through changes in posture, body language and approach towards the researcher. Participants were hospitable and welcoming, irrespective of whether the interview was taking place in their own home, in the ward or during their shift.

All the participants were keen to contribute and have their say during the semi-structured interviews, and the outline for each question was prepared to focus the participant but was rarely needed. The follow up meeting to read through the transcriptions gave participants a further opportunity to meet with the researcher and

talk about the study. Due to the structured method in recruitment, the researcher had already met with each participant four times before conducting the interview. There was evidence of trust from the participants, which can be seen when the researcher asked at the end of one interview if there was anything they would like to ask, one participant responded with, “...yes, *can you give me and her (pointing to the staff present) a lift to the doctors?*” (Theresa). This question from Theresa demonstrated a level of trust, in that she had confidence to ask the question in the first place and secondly trusted the researcher enough to get in the car.

## 4.5 Data collection

The interviews were audio recorded using an encrypted device approved by the university and the NHS, and then certified on entry to the units by security personnel. Once the interviews were completed the audio recordings were transported to the university campus following the agreed protocol and guidance on transporting data. This involved secure transportation, for example out of sight and stored securely in the boot of the car. The recordings were then subsequently uploaded onto a secure hard drive on a university computer, which was password protected and accessible only by the researcher. This took place the same day or the next working day where interviews were conducted on the weekend. Following successful upload to the secure hard drive the original recording was then deleted.

### 4.5.1 Stage 4: transcribing the data.

Following completion of the semi-structured interviews, the audio recordings were subsequently transcribed. The style and manner of transcribing differs and is largely taken for granted in qualitative research, although a researcher may develop a unique style through methodological and theoretical necessity (Blommaert, 2007). It was important in this study to transcribe all the data, although some sections were not relevant to meet the aims and objectives of the research study.

In this research study transcribing the semi-structured interviews served three purposes, particularly as the transcriptions were carried out by the researcher. First, by listening to the recording, stopping, and starting, and then working between the recording and writing up the narratives in a word document, the researcher was able to be immersed into the data. As the researcher conducted the semi-structured interview in the first instance, transcribing meant the researcher could recount the interview in a way that enabled closer observation of the narratives, and pragmatically write up the narrative. Secondly, transcribing the interviews enabled articulation of the narrative data into responses for each individual question. Locating responses into the corresponding question enabled the researcher to see how particular questions provoked more responses. Finally, the researcher was able to be reflexive about the interview technique. Listening back allowed the researcher to hear how questions were asked and how the interviews were conducted. Thus, the process moved from beyond description to a shaped story as told by each participant.

Participants were contacted to arrange a follow up meeting with a view to working through their interview transcript. This work through was intended to be supportive and person-centred, giving each participant an option of how this could be done. This individualised approach involved responding to the needs of participants, their circumstances and their individual needs and arrangements. The purpose was to verify each transcription, checking for accuracy as well as providing a final opportunity to withdraw from the research.

### **Transcribed data - The nurses**

The nurses were offered the opportunity to come onto campus, a face-to-face meeting or an electronic version posted via email. All the nurses decided to have their transcriptions sent to their work email address. Each transcribed document was encrypted with a secure password and emailed, with a second email then being sent giving each of the nurses a unique password to open the document.

### **Transcribed data - The women**

Checking over for validity with participants who have an ID can present practical challenges (Nind, 2008), in the sense of losing authenticity of the data because of the potential to over-interpret the material. In practice this approach took two different approaches. The purpose of this meeting was to go through the contents of the transcription of their semi-structured interview with each of the women. Thus, participants were asked to verify individual transcriptions for accuracy and to acknowledge that the written transcription was an accurate account of their words, to make sense of the interview and understand what the content said. This meeting was arranged around the requirements of each of the women. The reason this approach was taken was to take a final step in ensuring that the women were satisfied with the contents where there was a third party/parties present. During this final meeting it was expected that there would once again be a third party/parties present. Those staff present at the final meeting were different from the staff present during the semi-structured interview. Seven out of eight of the women took the option to meet in person to go through their interview account. One of the women (P12) asked for the transcription to be sent to the email account of her named nurse.

This approach also enabled a participant to go through the transcriptions and ask any questions they may have. Moreover, it was anticipated that some participants would require additional support to work through the interview transcription. This meant different interventions to different participants, including longer time needed to go through the text, one-to-one meeting, having a member of staff be present, or in four cases having up to three members of staff present. In all meetings with the women the transcription was read out to them. One participant had a learning difficulty in the form of dyslexia, and this meant additional support requirements were necessary. This required larger font size, extra line spacing and being printed out on pale blue pastel-coloured paper.

One of the women refused to leave her bedroom on the ward, declining to meet me for the work through of her interview transcription. She reported to the nurse in charge that she had since changed her mind and did not want any further

participation in the research. As there was nothing contentious about her transcription, there was no obvious reason for the withdrawal other than exercising the right to have a change of mind. In fact, it was noticeable that she was remaining in her bedroom and refusing to talk to me, and this was a strong contrast to the previous meetings in which she was friendly, helpful and contributed to the research. The change in response suggested a change in circumstances or indeed mental health. Whatever the reason the data from this participant was subsequently withdrawn from the data set, without prejudice.

Another one of the women was on a discharge plan from the unit when the interview took place, and this woman required three staff to be present. When returning to work through the transcription, armed with a good luck in your new home card, it was found that the woman had moved on to her new home already, away from the northern region, earlier than planned. The staff remained in contact with her to continue the support arrangements. We telephoned her new home, and she agreed for the nurse to take the transcription at her next visit three days later, and they would go through it together. The nurse contacted me after the visit to confirm the woman was happy for the interview to be included.

#### 4.5.2 Stage 5: data analysis

Qualitative research methods can be utilised to enable people with ID to express experiences in their own words (Ward and Trigler, 2001), as well as being able to articulate the issue in question. It has been acknowledged that research with people with ID should be inclusive and participatory (Walmsley, 2004), yet Kieran (1999, p.45) posits that emancipation and participation may be 'more a matter of emphasis than kind'. This research study explored experiences of the women and the nurses yet could not be participatory in this instance because the methodological approach was narrative using semi-structured interviews. The approach in the study did not include focus groups, and the decision to discount focus groups was made for several reasons. These included the issue of peer pressure, in the sense that the women and the nurses may report differently about their experiences in the company

of other women and nurses. The problems with utilising focus groups with participants who have an ID was presented by Barr *et al.*, (2003), who made the point that focus groups may not be a positive approach due to behaviour, communication difficulties and historical experiences. This is relevant to this research study as the participants were talking about their current/previous living or working environment. The concern was that participants may give responses in a focus group they think others want to hear, or similarly may avoid saying something that will have negative impact on their colleagues. A further concern was the representation on a focus group, namely who would be members of the group and how would the decision be made for inclusion/exclusion on the focus group. Furthermore, a focus group in this sense may have changed the research methodology completely into participatory action research, which has its place in research with participants and co-producers who have an ID but is less suitable here.

There were competing demands to be reconciled as to how the data would be most effectively collected. The aims of the research study was to listen to the accounts of the women and the nurses of their experiences of SS, and this reiterated the need for semi-structured interviews to be conducted in order to effectively collect the research data. Individual semi-structured interviews were decided as the best approach for this research study to best hear the lost voices of participants, which has been shown to empower a participant with ID by enhancing their knowledge and understanding of the world and their place in it (Atkinson, 2004).

Once the interviews were uploaded to a secure university drive, the audio recordings were transcribed by the researcher within two weeks. This process enabled an opportunity for reflection and a chance to corroborate the transcriptions with the verbatim notes that were taken when the interviews were carried out. More importantly, this process provided an opportunity for the researcher to familiarise and to get to know the data better.

Analysing data collected within narrative inquiry takes from the story itself and keeps the story intact (Riessman, 2008). It captures the composition of a response and relations between the researcher and participant, as well as the social and historical contexts (Riessman, 2003). The chosen analytical approach largely depends on the nature of the research and the reason for conducting the study in the first place, more specifically the rationale. Section 1.4 provides a rationale and justification for why this research study is needed. The intention in this research study was to analyse the collected data through a thematic analysis framework, based on Braun and Clarke (2006).

Holloway and Todres (2010) define thick description as a theoretical and analytical portrayal of individuals and cultures. As a result, it gives a rich depiction of the participants in the context of their culture, and in turn will enlighten the findings by contextualising the accounts given from participants. This will be broad and specific, as opposed to thin description, which is superficial and descriptive (Holloway and Todres, 2010).

In terms of analysing the data collected from the women, themes could have followed many paths. This includes subjects related to nursing, criminality, culture, behaviour, treatment, assessment, or trajectory of the women through SS. Conversely, data collected from the nurses could have related to clinical practice-based topics. For example, assumptions, practice, education, preparation, support or professional journey through working in female SS.

## 4.6 Thematic analysis

Once the interview was transcribed it was checked by the researcher for accuracy by listening to the interview and reading the text simultaneously, which contextualised the data. This also enabled the researcher to become familiar with the data. The data was placed into categories of the themes identified. Then there was a process of scrutiny to look for emerging patterns to code the data, using a broad outline of



codes that followed the Bogden and Bilken (1992) model. This model of approach includes setting/context codes, definition of the situation codes, perspectives held by participants, participants' ways of thinking about people and objects, process codes, activity codes, event codes, strategy codes, relationship and social structure codes, and methods codes. These codes were then analysed to identify any emerging themes which correlated to the aims and objectives of the research study. Narrative methodology means there will be first-hand information given from a participant about their experience, as well as interpretations of the actions of others. Thematic analysis is common in narrative research studies as it enables the researcher to look at the data in-depth. This style of analysing the data began with a review of the transcriptions to look for broad themes. This involved scrutiny of the words on a line-by-line basis. The transcriptions were read and re-read to look for commonalities and emerging themes, which emerged from collected data. The interview questions are provided in the appendices section, Appendix 1 for the women and Appendix 2 for the nurses and involved selecting/arranging into groups of text. Grouping of text in this way enabled the researcher to identify any themes emergent regarding the care, treatment, and management of women with an ID in SS.

Analysing the data thematically meant the researcher could analyse what participants said in a step-by-step way, thus aligning responses to questions and linking to the aims and objectives of the research study. It helped to look at the responses from the participants' own experience, particularly how they felt about their experiences and how they felt about themselves. This approach informed the research study in a way that provided an understanding and appreciation of what the ideology and beliefs are that have shaped the experiences of the women, as well as those of the nurses. This would appear to be a novel approach with participants who have an ID or are RNLDs. The researcher could listen to the shared experiences then analyse the data to best inform the findings. Table 7 below shows the steps that were taken to thematically analyse the data as adapted from Braun and Clarke (2006).

**Table 7: Steps in Thematic Analysis**

STEP	DESCRIPTION	WHAT WAS INVOLVED	OUTCOME FROM EACH STEP
1	Familiarisation with the data  Read and re-read with specific attention to what is occurring in the data	Conducted the interviews, field notes taken during the interview, transcribed the recordings, second meeting to verify content with participants and final opportunity to withdraw, colour coded transcriptions	Develop a list of start codes, what the codes mean and the source code.  Preliminary codes developed
2	Generation of initial categories from questions  Initial quotation, how and where patterns occur.  Data is complicated in this stage as researcher makes inferences regarding codes and what they mean. Data reduction into labels of each question to create categories for more efficient analysis	Re-read the transcriptions following validity with participants, looking at patterns and themes, arranged into data sets of each question.  Member checking data themes emerging with LD nurses and researcher.	Comprehensive codes developed that relate to research question.  Description and codes  Describe how and why codes combined and related.  Combine codes into overarching themes
3	Searching and identifying themes:  Define data and codes into themes.  Refine data in themes.  Describe what is missing from analysis	Carefully Define themes Search further for themes in transcribed data relating to defined themes.  Add or merge themes from across all data (not now purely question based analysis).	A list of candidate themes for further analysis
4	Reviewing the themes:  Linking themes to literature, aims	Search for themes in all transcribed data to correlate to current body of literature, to the aims and objectives of the research study.	Show how codes are related.  Coherent recognition of how themes are

	<p>and objectives and methodology.</p> <p>Include only relevant themes for further analysis.</p> <p>What is missing and incomplete</p>	<p>Research Journal notes need to include the process of understanding themes and how they fit together with the codes</p>	<p>patterned to tell an accurate story.</p> <p>Answers to the research questions and data driven questions, need to be complex and well supported by the data</p>
5	<p>Refining identified themes:</p> <p>Make decisions as to most important themes to include in the findings section. Based on those that linked more closely to aims and objectives</p> <p>Add in examples of narrative to illustrate themes from the data.</p>	<p>Define and ascribe a theme from the data interpret themes against research question.</p> <p>Ultimately define each theme, which aspects of data are being captured and what is interesting about the themes.</p> <p>Consider only the data that relates to aims and objectives of study and inspect themes against research question</p>	<p>Comprehensive analysis of how the themes contribute to understanding the data.</p> <p>Must describe each theme within a few sentences</p>
6	<p>Researcher writes report and decides which themes make meaningful contributions to understanding what is going on within the data (thick description).</p>	<p>Member checking (this study carried out member checking at beginning of data analysis)</p> <p>Go back to sample to check if description is an accurate representation of the data.</p>	<p>Finding's stage, thick description of the findings</p> <p>Note why some themes are more useful at making contributions and understanding what is going on in the data set.</p> <p>Describe the process of choosing the way in which the results will be reported</p>

## 4.7 Ensuring rigour

Rigour in research refers to the quality in the design and the depth to which the method has been followed within the research study (Lacey, 2015). The question around the trustworthiness of research centres upon the reliability and validity of the study (Leung, 2015). This research study explored the experiences of the women and of the nurses in SS specifically, particularly their own view of their own experiences. Consideration was given to identifying possible bias from the planning stage, with detailed plans on how the researcher would minimise the risk being developed. Table 8 demonstrates the reliability, validity and generalisability in the research study as adapted from Leung (2015).

Intellectual precision and methodological rigour assess the quality of a research study by applying three criteria: reliability, validity, and generalisability (Leung, 2015). In principle the meta-theoretical congruence helps to ensure ontological and epistemological consistency by balancing the philosophical assumptions with the area of study. Classically, this was described by Guba and Lincoln (1986) as credibility, dependability, confirmability, and transferability. This was then redefined as credibility, transferability, dependability, confirmability, and authenticity (Lincoln and Guba, 1995). This was supported by Forero *et al.*, (2018) as an effective framework to apply in qualitative research and no less rigorous than those applied in quantitative methods.

### 4.7.1 Reliability

The essence of reliability in qualitative research lies in the consistency of research practices which are transparent and evident in each stage of the research study (Cypress, 2017), as being open, honest, and stable. This gives integrity to the research study and precision in how the findings accurately reflect the data, also demonstrating reliability (Smith and Noble, 2014). Reliability in this research study can firstly be measured through the decisions made in the recruitment number of

potential participants. Similarly, Smith (2008) advocated that four to ten in-depth interviews are recommended for doctorate level research and recruiting vulnerable groups. This research recruited twelve women and twelve nurses.

Secondly, reliability can be judged against the review of the transcribed semi-structured interview data with each participant. Whilst it was more important to do this with the women, this stage took place with all participants. Stalker (1998) supported participant validation of interviews, particularly when participants have an ID, and this was developed further by Liamputtong (2007). Clarke *et al.*, (2005) used direct questioning with no abstract, theoretical or time inflections. This tactic meant that each participant could work through their individual interview and verify the transcription was an accurate record of what they actually said during their semi-structured interview. More importantly it meant that they could confirm that they understood the questions being asked during the interview.

#### 4.7.2 Validity

Validity in this research study checked the logic of the research question against the desired outcome, to ensure the method adopted was relevant to meet the aims and objectives of the research study. The data sampling and analysis was appropriate in order to contextualise the results and conclusions, because of the congruence in the methodology and method; meaning the intentions and choices were synonymous. Validity checks ensure the research study is systematic and rigorous, and that as far as possible the research is credible. Validity checks incorporated in this research study included balancing the ethical considerations with the agreed protocol and following the accepted ethical guidelines. Table 8 below gives an overview of how reliability, generalisability and validity were addressed in this research study.

**Table 8: Reliability, Validity and Generalisability**

Reliability	Thematic analysis enabled the researcher to carry out constant data comparison by progressing through the stages in analysis, documenting each stage and using tables to demonstrate how each stage developed into the next. There was constant use of the data. All stages documented in Chapter 5: Generation of data.
Validity	The research question was, "What are the experiences of women with ID of SS and how do nurses support them?" The aim of the research study was to explore the experiences of women with ID in SS and of the nurses who support them. A narrative approach was taken by means of semi-structured interviews to ask participants what their experiences were. The juxtaposition of the researcher as a RN and lecturer balanced the permeability of assumptions influenced by observations made, in the sense of what was observed with what was already known.
Generalisability	Participants recruited were women with an ID who are currently in-patients in SS, as well as Registered nurses currently working in the female ID secure service. Participants were also women with an ID who have previously experienced SS and nurses who have formerly worked in those services. This means the research study is focussing on specific populations, including women with ID and the nurses who support them in Secure Services. Therefore, the findings from the research study could theoretically be applied to similar populace. Such As women experiencing SS or about to enter women's ID Secure Services and Registered nurses who work or are about to work in women's secure ID services.

### 4.7.3 Mitigating bias

Bias can occur at any stage in a research study (Noble and Smith, 2015), from the design planning stage to the final data analysis stage. In a research study identifying and eliminating possible bias will ensure the research has trustworthiness and will ensure greater critical evaluation of the findings and conclusions (Smith and Noble, 2014). How bias was mitigated in this research study is summed up in table 9 below (adapted from Smith and Noble, 2014).

**Table 9: Types of possible bias and measures to reduce bias**

<b>Type of possible bias</b>	<b>Measures to reduce bias</b>
<u>Design:</u> Researcher's personal beliefs influence choice of question.	Personal bias is addressed in the methodology, method and analysis of data.
<u>Selection:</u> Process of inclusion and recruitment.	Strict inclusion and exclusion criteria as well as recruitment process approved by REC/HRA.
<u>Data collection and measurement bias:</u> Personal beliefs of the researcher affect the way information is collected or measured.	Semi-structured interviews conducted, recorded and transcribed. Validity checks with participants. Thematic analysis followed strict stages.
<u>Analysis:</u> When analysing data, the researcher overlooks data which confirms their personal experience or beliefs.	Stages in data analysis allowed personal reflection. The analysis followed the stages and was measured against personal experience and beliefs.

### **Design**

The research study was designed with the personal bias of the researcher in mind, and this was factored into the protocol and the decisions made in relation to how the study would be conducted, what the conceptual framework would be and how the data would be analysed. The design demonstrates congruence in the research

study, in that there is a fit between the intentions of the research study (aims and objectives) and the choices made (method).

## **Selection**

The selection criteria in the research study for research sites, sample size and participants were made to enable an ability to answer the research question. There was a strict inclusion and exclusion criteria which was applied when conducting the research study. In essence, this meant the study would recruit participants who were women and nurses from secure ID female services specifically, those that knew because they had in fact experience of secure ID female services. Consequently, participants would be able to answer the research question.

## **Data collection and measurement**

To mitigate the personal beliefs of the researcher, data was collected from participants by means of semi-structured interviews, recorded and fully transcribed. To focus the semi-structured interviews an interview schedule, one for the women and another for the nurses, was prepared with guiding topics within each question. As it was important to consider the fact that how the questions were asked would determine the elicited responses, closed or leading questions were avoided, and open-ended questions were used.

## **Analysis**

The data was analysed using thematic analysis, as this enabled the researcher to take a step-by-step approach to order, scrutinise and gather emergent themes from the data. A reflective journal was used along with a decision log, to enable the researcher to see the data from the perspectives of the participants and have a new way of thinking.



## 4.8 Patient and public involvement

Patient and public involvement (PPI) was an important consideration when decisions were made on the subject of the method of the research study. Factoring this in was an essential feature of the method, in so far as it was important to consult people with ID. The aim here was to consult with those who know, which in turn would inform the research. This informed the research in a way that would benefit participants by creating information that would enable participants to contribute to the study. This supports the work of Beighton *et al.*, (2017) who discussed the input of people with ID and families, which led to new insights not previously considered by the research team. Following the recommendations from Beighton *et al.*, (2017), consultation with people with ID in this way would ensure that PPI was authentic and not tokenistic.

PPI in this research study consisted of the researcher holding consultation events with a group of women with ID who were experts by experience (EBEs) and known to the researcher. This involved sharing the participant information sheets (PIS) in draft format for comments by EBEs. The draft format of the PIS was shared in this way to seek views and opinions about the document from a group of people who could best inform and advise. The following questions were specifically asked about the PIS:

- did this document (PIS) tell a potential participant about the research study in a way that they could understand?
- did the PIS state clearly what involvement would mean?
- did the PIS say clearly what the study was about?

Consulting with EBEs in preparing the supporting documentation in any research study is crucial. It was particularly significant to this research study since half the participants have an ID, and PPI could not be overlooked and was a serious consideration in designing the method in this research study. Seeking the specific views of people with intellectual disability was carried out to ensure the information was user friendly and accessible. The impact this consultation had was beneficial in

terms of gaining insight into the perspective from an EBE into the PIS and the research study as a whole. The consultation with EBEs resulted in the production of three documents. These were:

1. A participant information sheet for the women.
2. A participant information sheet for the nurses.
3. An information leaflet in an accessible format for all potential participants.

Three versions were produced due to the planned recruitment of the nurses and the women. An additional participant information leaflet was prepared in an accessible format, and this was informative and straightforward for all potential participants. Each participant information sheet (PIS) identified what would be expected of a participant and the questions that would be asked. All three versions of the PIS are presented in the Appendices section.

## 4.9 Ethics

### 4.9.1 Methodological Issues

An ethics protocol is fundamental in any research design and was an important consideration from the planning stages of this research study. There are several methodological challenges when participants in a research study have an ID, and one of the first considerations in designing this research study was not if the women should be included but how. A particularly beneficial starting point was to consider the key questions posed by Barton (1999), who warned against issues including who is this work for? What right do we have to undertake it? What responsibilities come with it? These questions are addressed in the decisions made by the researcher in consideration of the ethical issues. The ethical approval process and requirements needed before the study could proceed is discussed in section 4.9.5.

For this research study to proceed, permissions were required from the University Research Ethics Committee, the NHS Research Ethics Committee via the Integrated Research Application System (IRAS) and Health Research Authority (HRA), all

before approval from the individual sites is requested and granted. The request for ethical approval was highlighted as a major risk since half of the participants have an ID. The ethical approval system created the highest level of scrutiny, checks and balances required for any qualitative research study. A timeline of securing ethical approval is provided in the appendices section as Appendix 10.

#### 4.9.2 Ethical considerations for participants with intellectual disabilities

People with ID have tended to be overlooked in research studies, particularly women in secure ID services (Hellenbach *et al.*, 2014). As a consequence, many have not had an opportunity to speak about their experiences. Barnes (1996) warns against the role of ‘oppressors’, where there is a potential risk that the researcher is on the side of people with an ID or those in authority (Barnes, 1996). Conducting qualitative research can access the experiences of groups who lack the power to make their voices heard (Booth, 1996). People with an ID have something to say that is worth hearing and experiences that are worth understanding, making this important work worthy of serious attention, particularly considering the methodological challenges involved in researching this group (Nind, 2008). A participant may have vulnerability factors, for example mental health needs or sensory deficits. Thus, all the information was provided in accessible versions, and advice was sought on the accessibility of the language from people with ID.

In terms of carrying out research on sensitive topics, it is useful to look at the classic definition by Sieber and Stanley (1988 p49) which is ‘*Studies where there are potential consequences or implications for the participants in the research or for the class of individuals represented by the research.*’ This shows a need for a researcher in this context to be extremely cautious. There are intrinsic risks in carrying out research of any kind. What is noteworthy in this research study is the extensive experience of the researcher in the field of ID, via having over thirty years’ experience as a RNLD and a sound understanding of the difficulties presented when communicating with people with an ID. Furthermore, due to having an extensive background in ID nursing, this places the researcher in a favourable position to be able to understand any difficulties, to mitigate these or foresee any potential triggers

of distress before they arise, and alert supporters of any difficulties or discomfort should they arise.

#### 4.9.3 Establishing trust with participants – the women.

It is important to establish trust between the researcher and participant, with particular care given to developing a rapport (Walmsley, 2004). Research involving participants who have ID needs a further level of care and skill (Cameron and Murphy, 2007). This is because people with ID may not have the same social networks as the non-ID population, and their networks may primarily consist of professionals (Pockney, 2006). These issues were considered by the researcher in the design stage and application for ethical approval.

#### 4.9.4 Potential for disclosure

Clearly in a research study of this nature there is the potential for disclosure of an issue of safeguarding, particularly those which may be of a sensitive type and may well involve details associated with offending, abuse, or a safeguarding issue. The combined experience of the researcher coupled with the expertise of the clinician supporting the women enabled a professional relationship to be established to enable the researcher to manage such disclosures effectively, should they arise. In the event of such a disclosure, the researcher would engage the participant by reassuring them that this information would be appropriately referred and dealt with. That said, no disclosures were made by the women or the nurses in this research study.

It was important to not overlook the ethical considerations for the nurses who participated in this research study. The nurses who were subsequently interviewed were informed in advance of the interview format, what their involvement would be, and furthermore that all data collected was completely anonymous. The anonymous nature of participation, and of how it could not impact upon their professional development or appraisal, was highlighted. Despite this, the offer to the nurses to

come onto campus for their interview this was not accepted. This was an attempt to eliminate any possible bias and meet them away from the usual clinical environment.

Additionally, some of the participants will have had contact with the criminal justice system, which also raised further ethical concerns. This was because the questions may provoke uncomfortable memories or feelings about the women's involvement within the legal system. This in turn could have meant that a participant had different expectations, would be seeking clarification, or wrongly believed participation in the research study would help with any personal legal matters and/or to improve their personal circumstances. Were these issues raised, participants would be signposted to the usual sources of information. That said, they did not arise as a point for clarity during the interviews.

Any issues of misunderstanding or unrealistic expectations were addressed at the earliest opportunity, specifically at stage 2. Here, all potential participants were verbally provided with the information about the research aims, objectives and method. Stage 2 gave the opportunity for an information session, and thus enabled a question-and-answer session, to build on the information provided in the information sheets. The researcher facilitated discussion to take every possible step in ensuring participants were fully informed. This was revisited following the semi-structured interview, at stage 3. The option to withdraw without prejudice was pointed out at every stage in the research project. This was to ensure consent was informed and valid. Consent was established in three ways: informed consent (adequate information provided), voluntary (un-coerced decision) and competence (has the capacity to consent).

#### 4.9.5 Ethical approval

Both study sites were approved by HRA and IRAS as granted sites to accept the research study. The IRAS/HRA approval process involved scrutiny of the method because of the participants, specifically the vulnerabilities and how it was crucial that the researcher kept people safe throughout the study.

Keeping people safe was a significant concern in conducting the research study. Similarly, preparing and planning to conduct interviews with participants gave rise to a series of internal and external checks and balances. The nature of the research produced an alert which prompted the highest level of scrutiny to ensure the rights and dignity of participants remained paramount throughout. This was due to the potential vulnerability factors of the women. Justifiably, the issue of preserving and protecting the fundamental human rights of all participants was subject to a significant level of scrutiny and approval. The interview schedules were a major aspect of ensuring the participants remained safe. The schedules were prepared and submitted to the Research Ethics Committee (REC) via the Integrated Research Application System (IRAS), with a final approval granted from Health Research Authority (HRA).

#### 4.9.6 Consent and capacity

Capacity and consent are inter-dependent, and a participant could base their decision on whether to take part in the study from the information they received in the PIS. Capacity to give consent was a crucial aspect of this research, and all participants in this study were those who had capacity to consent. This is because consent must be informed, valid and expressly made, is decision specific and can fluctuate for many reasons. The option to withdraw without prejudice was pointed out at every stage in the research project to ensure consent remained informed and valid. Consent to participate was established in three ways, those being informed consent (adequate information provided), voluntary (un-coerced decision) and competence (has the capacity to consent). Consent was obtained at the beginning of the semi-structured interview.

However, it was acknowledged that capacity could fluctuate, and people changing their minds remained an ongoing consideration. A person with an ID is no different in this respect, and therefore information must be understood for consent to be valid. A detailed approach was taken to ensure that all participants are fully informed, whilst

also being mindful of potential barriers in this area. Specific information provided in the information sheet outlined all the stages in the research process with emphasis on making sure the participant knew the nature of the research and what their involvement entailed. The information given was relevant and accurate to effectively inform all the participants. Terminology was not overly technical or complicated to ensure that everyone involved knew what the research was about, what his or her involvement was and how to withdraw.

#### 4.10 Chapter Summary

This chapter has discussed the method in this research study. This has been achieved by outlining the practical stages in terms of sampling, recruitment, data collection and analysis. Issues affecting rigour, reliability and validity have also been considered, particularly with respect to reducing bias. An account of the patient and public involvement (PPI) and the ethical considerations have also been presented in this chapter, with close attention to examining issues of informed consent.

## Chapter 5: Data generation and analysis

### 5.1 Chapter introduction

This chapter will discuss how data was generated and what data generation means, from the unique methodological standpoint taken in this research. By discussing how the corpus of raw data was analysed in a step-by-step approach, the chapter will show how thematic analysis (TA) was adapted from Braun and Clarke (2006) to generate then analyse the raw data to create themes. The chapter will demonstrate how the themes generated from the participants were brought together because of analysing the data sets from the women and the nurses, resulting in one data set. In order to present the steps taken in data analysis the chapter utilises tables as a way to clearly illustrate codes (segments of data), candidate themes (beginnings of a theme), and then the final themes that were generated. Finally, the chapter will present how the final themes will inform the discussion in a chronological format.

### 5.2 Data generation and methodological considerations

Data generated from interviews has been noted to be ubiquitous in research across social disciplines (De Fina and Perrino, 2011) and is referred to as the leading type of collecting data in qualitative research (Silverman, 2013). Data generation is a relatively recent concept, and it describes theory and methods of data collection, although some authors have replaced the term data collection with data generation (Goldkuhl, 2019). Data generation differs from data collection or data access, as these are mechanical processes and not linked to the conceptual framework. Data generation in this research involved conducting semi-structured interviews, including the presence of a third party, thematically analysing the generated data into codes and candidate themes, and finally creating themes.



The decision to collect raw data in this research study through semi-structured interviews ( $n=20$ ) was taken with the research question, methodology and ethical considerations in mind. Furthermore, the data generation model connects to the narrative approach taken in this research, by enabling the participants to tell their story in the semi-structured interview and the use of open questions. This meant that the experiences were socially produced and re-produced rather than inherent within individuals, and TA in narrative inquiry does not focus on motivation or individual psychology but seeks to theorise the socio-cultural contexts taken from the individual accounts provided by participants. A discussion of the inclusion/exclusion criteria, recruitment of participants and how the semi-structured interviews were organised and conducted is provided in section 4.4.

The method of data generation in this research is inductive, created by the researcher and can be likened to the Big Q data analysis (Terry *et al.*, 2017). This meant a creative, organic approach to coding and theme development was taken. The themes were not waiting to be found (as in small q data analysis), so the researcher was able to create the themes from the generation of data from hearing the narrative. Nonetheless, the researcher was able to generate data through the theoretical framework, knowledge of the area and research skills at the time.

The unique methodological approach taken in this research study involved interviewing the women with a third party/parties present during the semi-structured interviews. This approach was crucial to the design of the research and is discussed in section 4.4.3.1, while the findings of the approach is presented in section 6.2. This aspect of the research study correlates to a data generation model by creating a powerful data generation opportunity because of the influence and interaction of the other parties who were present.

### 5.3 Data analysis

Qualitative data can be analysed in many ways, for example content analysis, interpretative phenomenological analysis, or thematic analysis (Miles and Huberman, 1994). The purpose of analysing qualitative data is to explore the content in the account on a deep level, and one way of doing this is thematic analysis. This approach is used to scrutinise the data in a close way, enabling the researcher to understand, interpret and represent the data (Braun and Clarke, 2006). Thematic analysis in healthcare research has been tacitly tailored to discover and classify patients' experiences of illness (Rasmussen *et al.*, 2000; Goodman, 2004). The flexibility in TA enables the researcher to focus on what was said (as opposed to how or why) and retains the narrative in its pure form (Reissman, 2008). Applying TA in this research suited the methodology since different combinations are possible and there are no rules, although the finished product should (and does) demonstrate what was done and why.

This research study used TA to delve into the accounts given by each participant and to systematically read, on a line-by-line basis, the transcribed data from the semi-structured interviews. This enabled the scrutiny of the data sets for emergent codes, candidate themes and then finally themes. Thematic analysis was applied in this research study by following the structure provided by Braun and Clarke, (2006), where the themes are categories. Each category is found by the researcher from the data then linked to the research topic and question. This produced a foundation for speculative understanding of the data, by seeing the themes as the data unfolds, in that the data was informing the researcher. This links to the epistemological and inductive paradigm which is discussed in section 3.4.1. The decision to choose TA in this study was taken because this approach enabled analysis to be undertaken in stages, through listening to the data, returning to the data sets and forming codes, candidate themes, then themes and sub-themes. This means that the researcher left no stone unturned. This built from the point of conducting the interviews, then the transcribing process and subsequently analysing the data to see the emergent themes. This meant the researcher could delve deep into the raw data to look for patterns and points of interest linked to the aims and objectives of the research

study. The thematic approach to analysis in this research study built upon Braun and Clarke (2006), as illustrated by table 10, which shows the deviation used in this study. In this case, the steps were followed and added to, which was necessary because of the nature of the research aims and objectives, the distinct needs of the participants and the innovative methodological approach applied in the research.

Table 10 below illustrates the steps taken in TA, which is presented with an element of reflexivity, showing the researcher as an independent reflexive analyst with an approach aligned to Braun and Clarke's reflexive thematic analysis (2019). One example of this is decisions taken in Step 2b, where steps were followed from leading researchers but not as rules. This is because it was important to remain faithful to the generated data, returning to the data sets to ensure the candidate themes were from the participants as opposed to the research question or interview guides.

**Table 10: Steps taken in the research study to thematically analyse the data as adapted from Braun and Clarke (2006)**

Step number	Description	What was involved, how I did it	Outcome from each stage of analysis
Step 1	<b>Familiarisation with the data</b> , read and re-read with specific attention to what was occurring in the data.	Conducted the interviews, audio-recorded and some field notes were taken during the interview, then transcribed the recordings. A follow up meeting was held to verify content with participants and final opportunity to withdraw, then the transcriptions were colour coded into questions.	Developed a list of start codes (a segment) relating to the interview questions, preliminary codes developed, what the codes meant and the source of the code.
Step 2	<b>Generation of initial categories</b> from questions. Initial quotations, how and where patterns occur. Data is complicated in this stage as researcher makes inferences regarding codes and what they	Re-read the transcriptions following validity with participants, looking at patterns and themes, arranged into data sets of each question. Member checking emerging themes with academic supervisor who also is an RNLD. Data was reduced into labels of each question to	Comprehensive codes developed that relate to research question. Description and codes. Describe how and why codes were combined and related. Combined codes into overarching candidate themes.

	mean.	create categories enabling more efficient analysis.	
Step 2b	<p>This analysis was data driven, and I followed steps of well-known researchers, not rules. As the data was driving the analysis, it was important to diverge from the steps when the data indicated that further analysis may be required. The themes were directly related to my questions and my interpretation, and I realised that certain questions generated more responses. Therefore, there was a lot more information that participants wanted to share, so I had not fully analysed or felt that it had not been fully verified in the coding. So, I went back through the raw data and looked at what the participants were saying, without full reference to the questions generated by me. This meant that the candidate themes were truly from the participants and not merely from my initial questions, which is why I used narrative approaches. As I went through the data, I realised that participants were adding to the data from questions I had not asked, but that were so important to the study. This was related to the prevalence of the themes in the data. Therefore, I returned to the raw data and looked at what participants talked about. I was only looking at the data through my questions, therefore my lens. This was going against everything I'd set out to do (to give them a voice), therefore I had to go back and try to utilise the lens the participants had. This would make my data analysis authentic and trustworthy.</p>		
Step 3	<p><b>Searching and identifying themes</b></p> <p>Define data and codes into themes.</p> <p>Refine data in themes.</p> <p>Describe what is missing from the analysis.</p>	<p>Carefully define themes</p> <p>Search further for themes in transcribed data relating to defined themes.</p> <p>Add or merge themes from across all data (not now purely question-based analysis).</p>	<p>A list of candidate themes for further analysis</p> <p>Some candidate themes were not true themes, as there was not enough data to support this as an important code and/or the themes were too diverse for this study.</p>
Step 3b	<p>The candidate themes were too large. Therefore, for time and data management, I had to then relate those themes to my aims and</p>		

	objectives and the research question. Because there was a mass of data, there could be a potential for some of the candidate themes to not be relevant to this study, but they were still nonetheless important. This made sure that the themes for the next stage were manageable, on topic, and the most important for the study.		
Step 4	<b>Reviewing the themes:</b> Linking themes to literature, aims and objectives and methodology. Include only relevant themes for further analysis. What is missing and incomplete.	Search for themes in all transcribed data to correlate to current body of literature, and the aims and objectives of the research study.  Research journal notes need to include the process of understanding themes and how they fit together with the codes.	Show how codes are related.  Coherent recognition of how themes are patterned to tell an accurate story. Answers to the research questions and data driven questions need to be complex and well supported by the data.
Step 5	<b>Refining identified themes:</b> Make decisions as to most important themes to include in the results section, those that linked more closely to aims and objectives. Add in examples of	Define and ascribe a theme from the data and interpret themes against research question.  Ultimately define each theme, which aspects of data are being captured and what is interesting about the themes.  Consider only the data that relates to aims and objectives	Comprehensive analysis of how the themes contribute to understanding the data. Must describe each theme within a few sentences.  Each theme can be located in raw data, and I must be convinced that the theme was real, and an accurate representation of what the candidates said.

	narrative to illustrate themes from the data.	of study and inspect themes against research question.	
Step 6	<b>Researcher writes report</b> and decides which themes make meaningful contributions to understanding what is going on within the data (thick description).	Go back to sample to check if description is an accurate representation of the data.	Results stage Thick description (findings) Note why some themes are more useful at making contributions and understanding what is going on in the data set. Describe the process of choosing the way in which the results will be reported.

## 5.4 Thematic analysis: Step 1

At step 1 the researcher transcribed the audio recordings from the semi-structured interviews and produced verbatim accounts, meaning there were twenty sets of data. This step enabled the researcher to become immersed in the data, to work independently and to colour code responses in relation to each question posed to a participant.

The next stages in data generation follow, and they set out the themes that are viewed as important to this study. It is necessary now to show how the direct quotations led the researcher to certain themes. It is unmanageable and ineffective to show examples for all of the themes, therefore the themes will be briefly shown, and their generation reflected by direct quotations from the specific narrative of the women and the nurses, using an example of one theme related to the aim and objectives.

## 5.5 Thematic analysis: Step 2

Step 2 involved putting the raw data from each question together, from the questions to the nurses and to the women. The data were then categorised into questions and grouped into responses from each participant looking for patterns and themes. This generated initial codes, which can be seen in table 11 for the women and table 12 for the nurses in the appendices section. This step included highlighting in the data the presence of staff and where their contribution was in the initial code.

## 5.6 Thematic Analysis: Step 3

At step 3a the codes were then ordered into candidate themes and aligned to the objectives of the research study. It was important to the research to link the candidate themes to the aims and objectives, not just the research question. It is noteworthy at this step to highlight the point that some candidate themes were not strong enough, as they were merely interesting to the researcher or too diverse for



the study. As a result of this they were discounted as outside of the aims and objectives of this research study, although there may be an opportunity to revisit those candidate themes at a later juncture.

The candidate themes from the women and the nurses were then linked to the objectives of the research study. A definition and discussion of each candidate theme and an illustration of the objectives they are aligned to is presented in the appendices section (table 18 Candidate themes from step 3 – The women and table 19 Candidate themes from step 3 -the nurses).

Step 3b involved integrating the themes from the women and the nurse into one, whilst retaining the link to the aims and objectives.

Objective 1 was to develop innovative qualitative methodological approaches in exploratory research with female patients who have an ID and are in secure services. The analysed data produced the following areas:

- Staff present during semi-structured interview and contributed.
- Conversing and discussing
- Corroboration
- Reminding
- Triangulation
- Specific learning difficulty

Objective 2 was to explore the treatment of women with ID by SS based on the lived experiences as told by women and the nurses, and produced themes in the following areas;

- |                        |                      |
|------------------------|----------------------|
| • The ward             | • Male/female        |
| • Sexuality            | • Treatment          |
| • Comorbidities        | • Discharge planning |
| • Multiple assessments | • Relationships      |

- Living a community life
- Detainment/seclusion/restraint
- Independence
- Typical day
- Choice
- Peers
- Independence
- Family
- Wider staff support
- Crime
- Incidents
- Medication
- School education
- Non-engagement
- Everyone is happy

Objective 3 was to examine/explore the nature and provision of significant support provided to or accessed by women with an ID in secure settings and produced themes in the following areas:

- Historical involvement
- Prison/young offenders
- Trauma
- Vulnerability
- Same/different
- Male/female
- Negative
- Positive
- Activities
- Friendships/peers
- Staff
- Male/female
- Best place
- Advice
- The nurses
- MDT
- Family contact
- Sexuality
- Family
- Trauma
- Ability
- Models of nursing intervention
- New ways of working for nursing staff
- Inter-professional working for engagement
- Engagement
- Possession of the women

Objective 4 was to explore the preparation and provision for practice for RNs working in SS, and the themes aligned to this objective were:

- Students
- Future advice
- Possession
- Learning on the job- in at the deep end
- Further training
- Possession
- Transient workforce
- The right person for the job
- Future proofing
- National/professional recognition
- Implementing and driving change
- Improved staff support - evidence based
- Role modelling
- Female/male
- Idealism
- Supporting student nurses

## 5.7 Thematic analysis: Step 4

At this stage, the candidate themes from the women and the nurses were brought together, and this was to integrate themes from all participants into one final set. The reason for this was to assimilate themes into one data set. The consequence of not taking this step would mean the themes and findings would have been two separate studies. Since this research was one study, it was crucial to consolidate the themes from the women and the nurses into one.

The themes at this step were;

- Journey
- Current experience
- Victims
- Condition
- Gender
- Relationships
- Long term planning – the end game
- Future nurses
- Behaviour and practices of the nurses supporting the women
- Preparing for the job
- Doing the job
- Behaviour and practices of the nurses supporting other nurses
- Treating the women
- Collaborative practice
- Supporting the women – long term planning
- Gender
- Sustaining a service

## 5.8 Thematic analysis: Step 5

This step involved a detailed analysis of how the themes provided an interpretation of the data. Each theme could be concisely explained and could be found in the raw data. This meant that each theme was a true reflection of the responses from the participants, as it was from their own words.

## 5.9 Thematic analysis: Step 6

This stage involved looking closely at the themes to produce a thick description of each one. It was necessary at this stage to make decisions about themes that were meaningful to the research or interesting to the researcher. This step in the analysis meant the themes that would be reported in the findings were aligned to the aims and objectives of the research study.

The themes were extensive due to the significant amount of data produced, which is unsurprising since the participants were twenty and there was 733 minutes of interview recordings. There were various ways attempted at this stage to decide the best way to present the data in the findings chapter. One possible way was to present the findings in a way that mirrored the order from the participants, in terms of how they answered each question. This was discounted because it would mean the findings could only be presented in two data sets; one for the women and another for the nurses. The flexibility in thematic analysis means that decisions by the researcher are encouraged. Moreover, it was decided to illustrate the findings and discussion from the themes in three chronological sections. These are Part A: Experiences from the past, Part B: Experiences of the present and Part C: The Future. This best reflects and keeps intact the narrative in the best way possible, and is shown in Table 13 Chronology, themes, and sub-themes, included in section 6.1.

## 5.10 Chapter summary

This chapter has discussed what how the data was generated, and what data generation means, from the unique methodological standpoint taken in this research. By discussing how the corpus of raw data was analysed in a step-by-step approach, the chapter has shown how thematic analysis (TA) was adapted from Braun and Clarke (2006) to generate then analyse the raw data to create themes.

Demonstrating the decisions taken in each step to analyse and generate further data by setting out each step, including the outcome of each step in the process. The chapter has used tables as a way to clearly illustrate steps taken to identify codes (segments of data), to then form the beginnings of a theme - a candidate theme, and then the final themes that were generated. Thus, it has been shown how the candidate themes from the women and the nurses were consolidated to create one data set. Finally, this chapter has illustrated the themes aligned to the aims and objectives of the research, by presenting the chronology of the data in the manner of past, present, and future which, will inform the discussion.

## Chapter 6: Findings and discussion

### 6.1 Chapter Introduction

This chapter will present the findings and discussion from the themes which emerged from the data analysis. The decision to unite the findings and discussion was taken as a result of the way the participants talked about their experiences. The women and the nurses told of their experiences in a chronological order, what happened to them before now, what their experiences are now and what they are looking for in the future. The chapter mirrors this by presenting the discussion and findings in the chronology of the past, present and future to best represent the narratives. To narrate the story in the way the participants did, this chapter remains faithful to the data and demonstrates the findings in a sequential order. Thus, data are presented chronologically in the style of past, present, and future.

This chapter illustrates how the theme relates to the principal research question, which was to explore the experiences of women with an ID of SS and how the nurses support those women. To show the importance of the theme a description will be given with extracted examples from the data, as individual direct quotations as said by participants. At times examples from the data contain profanities which are presented to show the level of emotion as told by participants in a way that will support the importance and prevalence of the theme from the data. Since data analysis in this research study is inductive, the extracts will be shown in an illustrative way, as opposed to an analytical format (Braun and Clarke, 2013). Thus, illustrating the extracts as an example of the analytical claims made in the research findings, as opposed to discussing particular aspects of an extract without providing the actual quotes from the participants.

## 6.2 Philosophical concepts

The aim of the research was to explore the experiences of women with an ID (the women) within secure services (SS) and how registered nurses (the nurses) support those women. Although the theoretical framework applied in this research study is discussed in section 3.4, it is important here to revisit the overarching philosophical concepts in relation to the findings from the data. Since the research is positioned within a social constructivist paradigm, a narrative approach was taken to hear from the women and the nurses about their experiences of female secure ID services.

Participants in the study were from research sites A and B, and study site selection and recruitment methods are discussed in section 4.3. Site A currently provides secure women's ID services, whereas site B is an area that previously provided the service but no longer does, and instead they provide community support for the women that were discharged from the service. The journey of the women has a similarity in that they have all experienced SS within site B at some point. Following service reconfiguration and subsequent ward closures the women were moved out of Site B. They were then repatriated to community living, or to another in-patient secure service in Site A. This movement was triggered by closure of services from policy change as a result of implementing the Transforming Care agenda (Bubb, 2014), as opposed to an improvement or deterioration in the women's behaviour or health.

There were five women currently in the secure female ID services at Site A and three who had previously accessed SS at Site B. For relevance to this chapter a brief overview and background of each participant is shown below in Table 11 and 12. For the purposes of retelling their story participants have been given a female Christian name as a pseudonym. Quotes from the nurses are shown in the chapter using the given pseudonym with an added prefix of Nurse.

**Table 11: Brief background of participants – The women**



<b>Patient participant pseudonym</b>	<b>Currently residing in female Secure ID service Y/N</b>	<b>Previously residing</b>	<b>Admitted from</b>	<b>Length of time in secure service</b>
P12 <b>Lauren</b> Patient	✓	Children's Secure Service	Children's Secure Service	1 year
P13 <b>Margaret</b> Patient	✓	Prison/ Community	Community	18 months
P15 <b>Olivia</b> Patient	✓	Children's Secure Service	Children's Secure Service	2 years
P16 <b>Penny</b> Patient	✓	Women's ID Secure Service	Women's ID Secure Service	12 years
P17 <b>Pamela</b> Patient	✓	Prison/ Secure Service/ Community	Secure Service	10 years
P18 <b>Ruby</b> Patient	✓	Women's ID Secure Service	Women's ID Secure Service	8 years
P19 <b>Steph</b> Patient	X Own home	Children's Secure Service/ Women's ID	Women's ID Secure Service	12 years

		Secure Service		
P20 <b>Theresa</b> Patient	X Own home	Women's ID Secure Service	Women's ID Secure Service	14 years

Table 12: Brief background of participants – The nurses

Nurse participant pseudonym	Length of time qualified as LD Nurse	Previously HCA Y/N	Working as RNLD Y/N	How educated to RNLD
P1 Nurse <b>Amy</b>	10 years	✓	✓	Hospital-based training school
P2 Nurse <b>Bella</b>	8 years	✓	✓	Hospital-based training school
P3 Nurse <b>Charlotte</b>	5 years	✓	✓	University Diploma - seconded
P4 Nurse <b>Davina</b>	2 years	X	✓	University BSc- bursaried
P5 Nurse <b>Emma</b>	15 years	✓	✓	University Diploma - seconded
P6 Nurse <b>Fran</b>	33 years	✓	✓	Hospital-based training school
P7 Nurse <b>Grace</b>	32 years	✓	✓	Hospital-based training school
P8	28 years			University

Nurse <b>Hannah</b>		✓	✓	Diploma - seconded
P9 Nurse <b>Ivy</b>	34 years	✓	✓	Hospital- based training school
P10 Nurse <b>Julie</b>	14 years	X	✓	University BSc- bursaried
P11 Nurse <b>Karen</b>	18 months	X	✓	University BSc- bursaried
P14 Nurse <b>Natasha</b>	3 months	X	✓	University BSc- bursaried

There were two interview schedules that were referred to during the semi-structured interviews: one for the women and one for the nurses. Both consisted of open-ended questions and topics within each question. There were five general questions asked of the women and three of the nurses. How the semi-structured interviews were conducted is discussed in section 4.4, and the interview schedules are provided in the Appendices section (Appendix 1 and Appendix 2).

The questions asked of the women were:

1. Can you tell me about what led you to being here?
2. What is your experience of female secure services?
3. Can you talk me through a typical day?
4. Where are your best relationships?
5. Where do you get most support?

The questions asked of the nurses were:

1. How do you support women with an ID?

2. How prepared and trained do you feel to engage and support women with an ID?
3. How do you feel you might develop this approach both in the short and long term?

There were different questions asked of the women and the nurses because both sets of participants would have something different to say on a subject. What is shown in the themes is how both groups talked about the same subject from their own lens. The data are presented as an aggregate of narratives from the nurses and the women, as each has relevance to the other. Presenting the findings separately for the nurses and the women would have missed an opportunity to look at how the narratives both corroborate and contradict each other, in terms of understanding the experiences of the women and the role of the nurses in supporting them. How the themes and sub themes have informed the findings and discussion in the research are presented in table 13, Findings: chronology, themes, and sub-themes.

The emergent themes from the participants will be discussed by giving an overview of each theme followed by an in-depth discussion of the sub themes. Background, context and empirical evidence are shown to critique each sub theme, thus demonstrating how each theme and sub theme relate to the aims and objectives of the research study. Themes from participants are set out in a way that is in keeping with the narrative approach in the study, by showing the themes in the way the participants talked about their experiences. This correlates with the overall research question ‘what are the experiences of women with an ID of SS and how do the nurses support them’? The best way to do this is illustrate the findings and discussion from the themes in three chronological sections. These are Part A: Experiences from the past, Part B: Experiences of the present and Part C: The Future.

**Table 13: Findings: chronology, themes and sub-themes**

<b>Chronology</b>	<b>Theme</b>	<b>Sub-theme</b>
<b>PART A</b>	Journey	Historical involvement in services

<p><b>Experiences from the past</b></p>	<p>Identity</p>	<p>Multiple placements  Moved away from family/friends.  Transience as a positive  Preparing to do the job/In at the deep end.  Career trajectory  Further training</p> <p>Diagnosis  Trauma Abuse Survivorship  Exploitation  Multi assessments  =Comorbidities  Criminal behaviour  Instinctive characteristics  Endearment  Possession  Trauma</p>
<p><b>PART B</b></p> <p><b>Experiences of the present</b></p>	<p>Current experience</p> <p>Relationships</p>	<p>Daily living in the ward  Liberty  Incidents  Independent living  Violence and Aggression  Friendly staff/saying the right thing.</p> <p>Peers  Family  Intimate/Sexual  Nurses  Staff Support  Inter Professional Working</p>

	Gender	Gender of staff Gender bias in service provision Mixture of Female/Male staff
<b>PART C</b>  <b>The future</b>	Long term planning	Discharge Community living Best place Advice to nurses Advice to students

Each theme presents the background of the participants and the situational context of their journey, in terms of where they have been, where they have come from and how they came to be in a female secure ID service. It also includes what has led to the women being in the service, and how the nurses perceive their preparation for the role in female secure ID services. Similarly, the nurses acknowledged the extensive journey these women had experienced.

## PART A: Experiences from the past

### 6.A.1 The journey

This theme relates to the lives of individuals as told through their own stories about their journey, and how they described their transition through SS or their career trajectory. This presents the story from the beginning, with the overarching theme of the journey. The sub-themes within this theme are historical involvement in services, multiple placements, moved away from family/friends, transience as a positive, preparing to do the job/in at the deep end, career trajectory and further training.

#### *6.A.1.1 Historical involvement in services*

The women were involved with services over a prolonged period of time, in many instances from an early age. Notably, the women told of their experiences from a range of services including health, education, and/or social services from childhood. The women were subject to professional involvement in terms of assessments, diagnoses, treatment, and multiple placements. Lauren was admitted to the secure service from children's secure service one year ago:

*"I came from [\*] hospital, so I was at [\*] ward ...before that at [\*] Hospital and then I went from children's to adults and then I came from [\*] hospital to here..."* (Lauren).

She also told the researcher that she has been admitted to four different services prior to this one.

*"...so technically what has led me to come to hospital is because I was unwell at home... they didn't know what was wrong with me so I was in [\*] Hospital like as an inpatient to get assessed to see if I had epilepsy and stuff like that"* (Lauren).

Lauren accepted her impermanence with services and reconciled this with the need to have a diagnosis, and the numerous professionals and services were helping her to achieve this. This model of intervention mirrors the care programme approach (CPA), where services and professionals should work together in a joined-up approach to provide clarity for the person (NHS Choices, 2018). However, Lauren did not mention CPA at any point in her narrative and may not have seen this as the rationale. Despite this, research conducted by Alborez (2003) found those with ID home were usually removed from the family because of difficulties within the family, criminal behaviour by the person, or service shortages (Alborez, 2003). This could be a further explanation for the multiple placements relayed by the women.

The women talked about being removed from their family as a child and admitted into children's services.

*"... I used to live at home with me Mam and Dad and that didn't go very well and they put me in respite in to [\*\*]...the respite couldn't handle my behaviour either...I was violent all the time"* (Steph).

Here Steph attributed her aggressive behaviour as the reason for being removed from her home. Even though the behaviour is perpetuated when she is admitted into the respite unit in any event.

Noticeably, there was limited involvement with education for the women:

*“I was seven when I started school...”* (Theresa).

This experience opposes the national standard for special education which states that there is provision up to the age of twenty-five (gov.uk). The Warnock Report (1978) recommended the closure of special schools and stated that children with an ID should have a statement of education (SEN) to support the child in mainstream education, which was later criticised by Warnock herself (2010) as detrimental. From 2014, SEN was enhanced and became the education health care assessment (EHC). Despite the impetus in education provision to bring services together for the best interests of the child with an ID, it seems the women did not experience the best education.

*“... It wasn’t kind of the right school...”* (Olivia).

*“...I left when I was thirteen”* (Theresa).

Research conducted found that children in school with an ID were more likely to be victimised and engage in more fighting (Rose *et al.*, 2015). This could explain the divergent experience the women had in school. They may have been reluctant or unable to disclose the issues they were experiencing and accepted the victimisation, and it is known that actively seeking the views of children with an ID is limited (Lewis and Porter, 2004). It is evident from the data that the women did not have a positive experience at school, and no action was taken then they left, which unfortunately impacted on their adult life.

From children’s services the women were transitioned into adult services.

*“I went a bit off the rails in 2016 I would say, when I was about 17, I was admitted... into children’s ward...then at 18 I moved wards”* (Olivia).

Here there is an issue of society having children that are so damaged and vulnerable yet being unable to protect them within the current system. Olivia has been in services since the age of twelve. Women with an ID are admitted to SS because of challenging behaviour or crimes they have committed.



*“I set fire to the petrol station... I went straight from there to... prison and from that prison to here. It has been about 14 or 15 months that I have been here now” (Margaret).*

This supports the literature which states that the length of stay in high or medium secure units can range between five and ten years (Völlm *et al.*, 2017). It was also found that there may be no realistic chance of discharge after six years in SS (Völlm *et al.*, 2017). Despite having professional involvement from a young age, some of the women are still in SS as adults. Lunskey *et al.*, (2011) point out that patients with ID have a mental health and forensic involvement, are a distinct group and yet their needs are not being well met. This is important because it shows a long and divergent journey, and that the services chose where they were cared for, not the women themselves, which is crucial in illustrating the limited-service provision for the most vulnerable in society who require person-centred care.

Conversely, the historical involvement did have a positive outcome for two of the women. Steph recounted her journey from a geographical perspective:

*“...from home...I was in \* for a year and then they couldn’t do anything else with me so they sent me to Medium Secure right down in \* which is on the outskirts of Liverpool and I was there for a year and a half then they couldn’t handle me so I went to be nearer to home so I went to \* for three years... the home is \* where I started my parents are in \* I am in \* it is only through \* Village this is where my mam and dad are its only ten minutes away” (Steph).*

Her multiple placements took her from her parents, moving her to national placements across England, only to return to the same location with a short car ride to reach her parents’ home.

Similarly, Theresa told of her historical involvement in services:

*“ I was on [\*ward] in [\*hospital] I am 31 years old now, I was on the ward for 8 years, it was a high secure ward, before that I was in [\*] youth offending prison until I was eighteen” (Theresa).*

Livingston *et al.*, (2011) proposed the paradox that patients in SS are detained and services can only be person-centred where there are special interventions. Theresa told of her transient journey:

*“...from there on to [\*] the ward, I was in [\*] hospital I did look round [\*] hospital I was in [\*] hospital, when I was seventeen, so I went to [\*] youth offending, but I wasn’t there for very long then to [\*] hospital then to [\*] from seventeen to eighteen then I was transferred to [\*] hospital where I was in the ward for 8 years...”* (Theresa).

There is an important facet to Theresa’s story here, particularly as the literature supports the notion that the rate of success in SS is attributed to person centredness (Livingston, 2011). Theresa is one of two participants who are now living in the community in a supported living scheme.

#### *6.A.1.2 Multiple placements*

The women talked about being moved around the country for services with multiple placements, placed a long way from home, removed from family home and placed into children’s services. Participants also talked about transitioning from children to adult services, a range of secure wards and extensive lengths of time in each placement.

*“I have lived in Scarborough, I lived in a secure unit in Reading and a secure unit... I have been all over the place and I have been to a secure unit somewhere down South way so it is a little village like a little place you can’t get out of I have been in there, I have been in [Nottinghamshire] Hospital, not a secure unit there you can just go out when you want so I have been there, I have been to [\*] Prison I have been all over the place... I have been to [\*] Prison as well”* (Margaret).

Participants talked about being admitted to young offenders’ prisons and placements countrywide and told the researcher that geography had played a big part in their journey. A study by Bartlett *et al.*, (2014) found that a third of the female participants ( $n = 1149$ ) were placed outside their home region despite spare local National Health

Service (NHS) capacity. Nationwide provision includes the independent sector which provides for women with relatively rare disorders, including intellectual disability, and the NHS admits most serious offenders, with one in twenty being detained because of self-harm alone (Bartlett *et al.*, 2014). This illustrates that the NHS maybe first point of admission at a crisis point, then stepped down into services in private/ voluntary organisations.

Here Theresa decried being discharged into the community following the closure of the secure ward due to the implementation of the Transforming Care Agenda (Bubb, 2014).

*“...I was on [\*] in [hospital] I am 31 years old now... I was on the ward for 8 years, it was a high secure ward, before that I was in [\*] youth offending prison until I was eighteen...from there on to [\*]...in [\*] hospital I did look round [\*] hospital I was in [\*] hospital, when I was seventeen, so I went to [\*] youth offending, but I wasn't there for very long then to [\*] hospital then to [\*] from seventeen to eighteen then I was transferred to [\*] hospital where I was in the ward for 8 years. ” (Theresa).*

Meanwhile, Lauren stated:

*“I came from [\*] hospital, so I was at [\*] ward before that at [\*] Hospital and then I went from children's to adults and then I came from [\*] hospital...we moved because I was on [\*] ward like the old [\*] ward and stuff like that so I was on there for a couple of months and then I moved to [\*] ward where it was locked but we moved up to the new build on October 11<sup>th</sup>.” (Lauren).*

Palucka *et al.*, (2012) showed that those with an ID, MH and contact with CJS are more likely to be admitted to secure units, are not best served in those units and are admitted for more than one year.

*“I was admitted when I was...17 to children's...then I moved wards...It was [\*] hospital I was on [\*] and then I was on [\*] and then I was back to [\*] and back to [\*] and then I was here because they couldn't really decide what was the best support, but the thing is being on [\*] wasn't the best support” (Olivia).*

Steph illustrated the extent of multiple placements around the country and away from family.

*“...I used to live at home with me Mam and Dad and that didn’t go very well and they put me in respite...they couldn’t handle my behaviour...I was violent all the time then they found me a placement in[\*]...for a year and then they couldn’t do anything else with me so they sent me to Medium Secure right down in [Liverpool area]...there for a year and a half then they couldn’t handle me...now my mam and dad are ten minutes in the car away... I am 24 now”* (Steph).

However, this participant was recently and successfully placed within the community with extensive staff support in place. This illustrates that family-centred approaches can result in positive outcomes.

#### *6.A.1.3 Moved far away from family and friends*

The women described being moved away from family and friends, their home and support networks. Additionally, the women referred to episodes in their admissions in SS when it was logistically difficult for family to visit. Similarly, the nurses acknowledged the geographical difficulties placed upon the women.

*“I am not from around here...”* (Olivia).

The literature highlights that secure service provision for women with ID is located in coastal areas, away from urban areas, (often a significant distance from support services) and restricted to the North East of England (Harty *et al.*, 2012). The distinct shortage of SS for women with ID meant that those women were moved considerably around the country into areas where there was provision.

*“I can do what I like pretty much but it is a bit shocking because it is only an hour a day or if you are with family, it is extended which is better, but my*

*family can't come up here every single day because it is £10.60 on the bus... they leave at 9 am and they get here for 1, they get four buses" (Olivia).*

Similarly, the nurses referred to the issue of the women being placed far away from families, parents and even their own children.

*"Because they are away from family and they don't have their babies or their children with them and I think it is so difficult... her child was in London and she was in the North East...one lady...was in the ward for five years...until they found a place for her in Bradford" (Nurse Hannah).*

Here the participant was discussing case examples about the women she supported in the past when families were stretched across the country and placed in placements in yet another location away from family. The interesting point to note about the movement of the women around the country was it was as a direct result of service provision/availability or changes in policy.

#### *6.A.1.4 Transience as a positive*

The women accepted that moving around services meant they would encounter a range of professionals and peers.

*"my nurse [\*] on the ward, she respected me, I had never seen a squirty gun in my life, [\*] she got me one...I was at offenders and [\*] other hospital then she [\*] finally gave me a squirty gun, I was over the moon, I had never seen a one before in my life, I watched Tracy Beaker on the telly and that's what she did, [\*] knew I would do the same as Tracy Beaker so she expected it. She used to watch Tracy Beaker to know what I was thinking". (Theresa).*

Participants told stories with fondness and heartfelt memories, naming individual nurses they had encountered who had clearly had a lasting impression on them. This mirrors the evidence base where nurses are caring and flexible in an inflexible setting (Magnusson *et al.*, 2020).

The women referred to meeting former patients, forming relationships and meeting boyfriends or girlfriends throughout their journey. Thus being able to sustain relationships despite the transient aspects to their journey.

*“they made a newer one (hospital) so all the patients from (\*) got transferred over to (new hospital) and came over, I came straight from (Liverpool area) and I am glad I did otherwise I wouldn’t have seen my best mates, or I wouldn’t have met my lass” (Steph).*

#### *6.A.1.5 Preparing to do the job or in at the deep end*

The nurses gave their perspective on the preparation they had to do the job as a registered nurse learning disabilities (RNLD). They referred to the individual ways they took in qualifying as a nurse. Table 12 above provides a brief background of the nurses and illustrates the various routes of entry they took to Registered Nurse (RN) status, which included higher education or hospital-based training schools. The nurses described their transition from student to RN as being thrown in at the deep end. They spoke of learning on the job and the role of the university in their preparation for practice.

The nurses described how they felt they were not adequately prepared for their role as an RNLD in secure female ID services.

*“...there was no preceptorship then, you were thrown in at the deep end”.*  
(Nurse Grace). “

*When I first qualified you were thrown in the deep end a lot sooner so whether that is a good or a bad thing I don’t know because you learn to either sink or swim” (Nurse Julie).*

They described the transition from student to RNLD as having to learn to swim at the deep end without the opportunity first to learn to paddle in the shallow end.

*“...sort of put in at the deep end as I was still newly qualified through my preceptorship, but they were short staffed then” (Nurse Davina).*

*“...I did my training, and we were pretty much dropped in at the deep end...”*  
(Nurse Bella).

*“I don’t think you really learn the job until you actually start to do it...it’s very much learning on the job”* (Nurse Amy).

*“...kind of growing into the role...rather than coming prepared”* (Nurse Amy).

*“I don’t think you get that day-to-day experience even as a student you still have that protective factor where you are not dealing day to day with potentially highly aggressive situations to deescalate, then skills comes in time from working within the environment”* (Nurse Charlotte).

Here Nurse Charlotte linked the difficulty from being a student nurse to being prepared to do the job. Curiously, the nurses had the same to say in relation to student nurses who are placed in their service, with Nurse Bella stating *“...we drop them in at the deep end”*. Which is interesting since the nurses talked a lot of being dropped in at the deep end, and then took the same approach with student nurses who were learning the job. This suggests the practice of *‘being thrown in at the deep end’* is embedded into a learning culture and perhaps at times a positive approach to learning about the role as Registered Nurse Learning Disabilities.

The nurses stressed the importance of involving HCAs in decisions when they were learning how to do the job.

*“I think my biggest learning point was when I signed on to the bank as a health care assistant during my course, within this trust, I think that gave me more preparation”* (Nurse Charlotte).

The nurses believed their biggest learning opportunity was when they worked as an HCA themselves before entering nurse education.

*“I think initially when you first come into this setting as a qualified nurse, if you haven’t had any experience in the past, it can be quite daunting when you first come here”*. (Nurse Charlotte).

Reporting on the challenges associated with becoming a newly qualified RNLD, some reflected on what it was like qualifying in the 1990s.

*“I did my training in the nineties...I think even as a nurse you do your training, but it actually doesn’t teach you how to be a nurse I think you get that on the job”* (Nurse Bella).

They also referred to the availability of placements out of the trust site:

*“...three years training in the nineties which was placements elsewhere not necessarily within this hospital but a lot of them were, so you were quite well prepared...but on registration you were just given the keys and that was it, you were left to go”* (Fran).

Here Fran also described being put in at the deep end. It is known that staff working in women’s secure service are more likely to experience burnout than those working in males in SS (Nathan *et al.*, 2007), and being better prepared can only improve the issue.

*“...I was prepared because I had worked with females for 8 years... secure services is different to a degree because of the restrictions... moving from acute services...that’s the difference...I had to adapt and change my mind set but I was prepared to work with the females, and I didn’t feel much difference to be honest with you.”* (Nurse Julie).

*“... I’ve learnt on the job”* (Nurse Emma).

This shows the differences in the nurse education following the move to the graduate profession and the preceptorship programme. Although all the nurses felt the same irrespective of when they completed their programme, it was reported that learning disability nursing needs to carefully examine the skill and knowledge base required to work in secure settings (Lovell, 2017).



The nurses referred to the nurse education programme at university and how the course centred on evidence-based practice. Nurse education moved from hospital-based training schools to universities in 1999 to an all-graduate profession in 2015.

*“...I think even as a nurse you do your training, but it actually doesn’t teach you how to be a nurse I think you get that on the job” (Nurse Bella).*

*“I don’t think university really covers some of the things especially within our environment that you need to know” (Nurse Amy).*

Although this transition took place over twenty years ago, it was a significant move in nurse education. However there remained some difficulties, as expressed by Nurse Bella. Despite the complexities the nurses cope with and the demands placed upon them, they felt able to manage to provide person-centred nursing care and form appropriate therapeutic relationships with the women.

The perceptions of others are important in many respects, and it appeared there was a lot of myths and stigma in female SS.

*“I went to work into the male low secure ward one day and was told you are leaving... my heart stopped, and I thought I am going to female and my first response was what have I done wrong that was a lot of peoples reaction because they knew at that point it was a really difficult area to be in” (Nurse Hannah).*

Issues between safety of staff and scaremongering must were also balanced.

*“I had heard that no one wanted to work there or were very reluctant to go there” (Nurse Emma).*

This research shows that there are many positive aspects of female SS, yet Nurse Karen stated

*“...a lecturer said it was terrible, I am glad I don’t ever have to go back... it was just the way he portrayed it...I had this impression that I would come in and because of their diagnosis they would be really aggressive...” (Nurse Karen).*

In turn, this point was supported when another participant talked of her experience of the preceptorship programme:

*“you meet with the matron and trainers and you go through things such as seclusion...reflecting... and sort of validate our feelings against each other’s”*  
(Nurse Natasha).

This participant is three months into the role and gave her positive experiences of the current preceptorship programme.

The nurses in the study who qualified more than two years ago talked about how they were seconded by their NHS trusts from their role as a HCAs into nurse education or were trained in the hospital site in a nurse training school. Those nurses who attended nurse training school or were seconded relayed a sense of loyalty and appreciation from their journey:

*“I am lucky”* (Nurse Amy)

*“I consider myself lucky”* (Nurse Hannah)

Although the practice of secondment is currently limited in terms of the low numbers offered by the NHS, there are emerging alternatives to achieve RN status, for example trainee nurse associate (TNA) or degree nurse apprenticeship (DNA). One of the participants expressed her views about the new ways in nurse training:

*“I don’t agree with the nursing associate nurse... is a band 4 and the other one is a band 3 and sometimes they can do student type .... I don’t think it is good for our population... it is going to be difficult for our ladies”* (Nurse Bella).

Alternatively, the nurses who attended a university-based course and were paid an NHS bursary did not have the same attitude towards their education.

*“...you don’t get prepared through university this might sound negative... but I don’t think you get that day to day experience even as a student you still have that protective factor where you are not dealing day to day with potentially highly aggressive situations to deescalate, and all them skills comes in time*

*from working within the environment, so I think through university there isn't very much preparation really, to be honest, it is very much evidenced based looking through the research" (Nurse Charlotte).*

This shows how the nurses felt they were not prepared from a university course to take up the role as a RN in female SS.

Whether the nurses were trained or educated to do the job, they were all working in the role as RNLD. The length of time in the job ranged from 33 years to three months. The paradigm shift in nurse education has evolved even further with the removal of financial support three years ago. Those nurses will be taking up practice from September 2020 and were unable to meet the inclusion criteria for this research study. Therefore, it remains to be seen what this way of educating nurse will reveal and mean for the workforce in female ID SS. A further consideration will need to be made for the preparation and education of RNLDs in response to Covid-19 emergency standards for nurses (NMC, 2020). This is because the emergency standards have triggered nursing students becoming RNLDs six months ahead of time and paid placements were implemented.

#### *6.A.1.6 Career trajectory*

The nurses came into the profession through a variety of routes and had a range of experience in their nursing careers, and this diversity of roles is documented in the literature (Gates, 1997; Abdulla *et al.*, 2015). The years of experience as an RNLD ranged from three months to thirty-four years.

*"I did the old-style training...here in the hospital it was a nurse training school...the last placement was the female secure unit...you could choose where you went for pre staff nurse development, so I chose to stay there I think I was always destined, I was really really interested in the women... I finished off my training for the last seven months of my training working in female secure services ..., eventually I came back to work with the women...did so for about nine years on the ward, I would still be there if the ward hadn't closed" (Nurse Grace).*

A brief background of participants and the route the nurses taken in terms of training and education for the role as RNLD is shown in section 6.1 and Table 12.

Some participants began their journey as a HCA for a number of years and were then seconded to university for nurse education and registration.

*“I started my career as an HCA then I was seconded, I was lucky, I was lucky then a clinical lead and now ward manager, its people who haven’t got that HCA background they struggle the most, its invaluable, I’ve done that job, I know what’s expected, you have to know the basics”* (Nurse Amy).

Participants considered themselves to be fortunate in their career trajectory and lucky to be seconded into nurse education.

However, a determination to work in the female service was evident when a nurse resorted to leaving the organisation.

*“...I worked in males secure autism...for about two years and didn’t like it at all so I left the service, I went to the prison service still as a band 6...then CAMHS, then a band 6 came up here for females here so I was thinking, I’m coming back, I’m coming back...”* (Nurse Amy).

Here, Nurse Amy told the researcher of her determination to work in female services, how she moved around and even left her organisation. This trajectory of the nurses resonates with the journey experienced by the women, in that they were also to-ing and fro-ing to get to an ideal place.

The women’s secure service had negative press as a place of work.

*“I was offered a job in forensics and they asked me my preference and I said I would work on any of the wards, but I don’t want to work on women’s, and I think they must have said right now she has said that we are going to give her the women’s and to be completely honest I have loved it, I have really enjoyed working with the women”* (Nurse Hannah).

This nurse showed that being placed into the service against her wishes worked out in her favour, and again this point is resonant with the journey experienced by the women.

#### 6.A.1.7 Further training

The nurses referred to the in-house training they received to assist them to be able to do the job.

*“there is a lot of in-house training that’s sort of available to us... I just think it depends on what type of person you are... I think a lot of people come into our service that you know aren’t going to last...”* (Nurse Amy).

The in-house training provided for RNs in SS included courses on trauma informed care (TIC), leadership, autism, mandatory training, PD, DBT, PBS, coaching, physical health, sexual abuse, St Andrews forensic module and suicide prevention. Although the nurses reported that more detailed training was required on supporting the women and their families, physical health/Comorbidities, the need to know about pharmacology and more specifically anti-psychotics.

*“...doing a masters at the minute in management and leadership...also on the accreditation for the master coaching...all about coaching people rather than managing people...also doing that accreditation which has given me additional skills which I probably wouldn’t have had if I didn’t do the training, so I do think there are opportunities there”* (Nurse Bella).

The nurses had participated in continuing professional development by attending post-qualifying training in a wide variety of ways, ranging from short in-house training to master’s level degree qualifications.

*“Physical health training was available...cervical screening...psychology would do a lot of work with us, about behaviours related to hormones...personality disorder, bipolar, self-harm they are what they are...the interest I have for the job, also reading around subjects, attending*

*anything CPD that is offered in secure services... anything CPD related and probably because I am exceptionally interested in my job and I like to know"*  
(Nurse Emma).

The content of the education had also been wide ranging, including physical health, mental health, and psychology-based interventions. This showed how the nurses had an array of interests and an overall appetite for furthering their own knowledge in order to serve the women in the best way they can.

The journey experienced by the nurses differed in terms of how they were educated to do the job. Those nurses who worked as a HCA before being seconded into university considered themselves *"very lucky"* (Nurse Amy). Whereas those nurses educated primarily through university said, *"university does not prepare you adequately to do the job"* (Nurse Bella). Here there is a juxtaposition with the researcher, a former pupil nurse who progressed through a nurse training school, before attending university for further nurse qualifications and now working as an academic educating student nurses to achieve BSc/RNLD qualifications. The connection enabled the researcher to see how all avenues are different, and offer different experiences for a different journey, whilst achieving the same result.

#### *6.A.2 Identity*

This overarching theme represents how the women saw themselves and how the nurses saw the women. The sub-themes within the theme of Identity are diagnosis, abuse and survivorship, exploitation, multi-assessments = comorbidities, criminal behaviour, instinctive characteristics, endearment, possession and trauma. The women articulated their identity in a way that demonstrated their sense of self in many facets. The women had been exploited, abused, have co-morbid conditions and are criminals.

This theme shows how the women saw their own complexity from a young age, over a significant number of years or most of their life. Despite these challenges they

demonstrated a level of acceptance. Paradoxically, the nurses saw the identity of the women in a possessive sense, using terms of endearment whilst at the same time recognising their trauma. Ultimately the nurses talked positively about their skills to be able to support and treat the women despite the adversities, showing how they can implement anti-discriminatory practice.

#### 6.A.2.1 Diagnosis

The women saw their diagnosis as an important aspect of their experience. They referred to having a diagnosis of conversion disorder, mild learning disability or having no learning disability. The women seemed to medicalise themselves, which is interesting since the social versus medical model of disability is in favour of a social model for the rights of people with ID. Authors define the medical model as reactionary and the social model as progressive, championing the rights of disabled people by placing the responsibility on society (Shakespeare, 2006). Olivia made reference to a label of a diagnosis and her perceived identity because of it.

*“Because I started off with conversion syndrome and then then they said .... I have been diagnosed with lots of different things but then they have taken some of them away. I was diagnosed with conversion syndrome and that is borderline now...it is just what one of my questions is, is conversion a learning disability or is it a mental health. I am just confused because I have been diagnosed from the age of 3 with a learning disability” (Olivia).*

*“I was on the LD because I haven’t got mental health problems, I’ve got a mild LD” (Steph).*

*“It wasn’t kind of the right school because I don’t have a learning disability to be fair, I have got dyslexia, but the places were for learning disability although I had dyslexia which is a learning difficulty” (Olivia).*

A hierarchy appeared to be evident in the women’s narrative, ranking ID, LD and MH in a particular order. This was perhaps due to stigma or their own perceptions, particularly how they have been brought up to believe their identity was associated with a certain way, in essence stereotyping themselves.

However, the nurses' views were not focussed on a diagnosis.

*"a lot of the ladies also have their own diagnosis, and they sort of can support one another through these (sessions)"* (Nurse Davina).

Meanwhile, through TIC the nurses could see how diagnosis was previously a central focus of treatment but not anymore.

*"we have been much more diagnosis focussed ...with TIC we have a different way of supporting our patients..."* (Nurse Amy). *"the ladies we cater for are generally on the lower end, have a mild learning disability or borderline sixty or seventy...often their mental health or behavioural needs are alongside that and takes a fore front... not just focussing on risks or diagnosis which is obviously important, it's to help build their skills..."* (Nurse Charlotte)

The nurses did not pigeon-hole the women in terms of diagnosis, as their story was more focussed on anti-discriminatory practice and treating the women holistically.

*"...the tough thing about it is not holding grudges and that is what a lot of people struggle with. If you are hurt and you are verbally abused...literally just think these people are unwell and have got difficulties they are not doing this because you have done something they are doing this because of the circumstances that they are in, the life changes that they have got going on and because they are genuinely scared and upset and they are lost really I think. Their identify is now they are in this hospital like they are a patient in hospital they are not a mother, not a sister or a daughter anymore they are here, and they are fighting to try and gain their identity back and I think it is so hard"* (Nurse Emma).

#### *6.A.2.2 Abuse Trauma and Survivorship*

When the women were asked 'Can you tell me about what led you to being here?' (question 1), they narrated episodes in their life when they had been abused. They told the researcher about being abused by someone known to them or family members, lasting over a significant period of time, which is supported in the literature (Reiter et al., 2007).



*“When I was little, I was very badly abused from my dad, from being four years old up until I got married, that made me thinking emotionally...”* (Penny).

The prolonged abuse Penny suffered is synonymous with the literature, in that abuse can go undetected due to the lack of skills and training of RNLDs (Harrison, 2003).

Reflecting on the abuse she suffered, Penny continued her narrative by saying:

*“...I was at home in my own place...I was doing bad things to kids...which is why I came in ...”* (Penny).

She was telling the researcher about living independently, then continued her story to say she became an abuser, seeing this as the reason for her being in the secure service. More research is needed around women with an ID who are sexual abusers, since most studies have focussed on their male counterparts (Hellenbach *et al.*, 2014). Hollin and Palmer (2006) noted that female sex offenders have highly specific criminogenic needs, thus, a specific individual approach is needed to reduce the likelihood of recidivism. However, it is known that those with an ID are at a higher risk to being abused than the non-ID population (Reiter *et al.*, 2007). Yet there is little research seeking their views on the issue. One study found that being abused made them feel worthless, but discussing feelings helped see the impact the issue had on their lives (Northway *et al.*, 2013). Being abused by peers was described by a participant:

*“I was assaulted not by staff...she was violent...that happened to me all the time”* (Pamela).

Violence is noted to be a significant problem amongst those with ID, particularly in hospital settings (Taylor *et al.*, 2016).

Another participant told of how she was exploited whilst living in the community:

*“so, I was hanging around with gay people because I am gay myself, they were horrible...I was hitting [\*] but she wasn’t very good with me she was drinking and beating me up and being nasty to me and taking all of my money off me I didn’t like her but I don’t want to go to [\*hospital] either...”* (Margaret).

Here Margaret recounted her experience of being abused and how she was abusing others, and thus she has formed many unhealthy relationships. The sequela of abuse is an important factor in how the women understand sexual relationships (Eastgate *et al.*, 2011). Margaret was asserting her sexual identity but concurrently being exploited. Through sex education women with an ID have an understanding of

their sexual rights as well as the social discourse that prevents them from asserting sexual identity (Healy *et al.*, 2009). None of the women talked about receiving sex education. Staff and families need to have specific training to challenge their own ideological assumptions on sex education to enable the women to develop their sexual identity (Evans *et al.*, 2009).

Research is emerging to show that women with an ID who have experienced sexual abuse present with higher psychiatric disorder and challenging behaviours (Sequeira *et al.*, 2003). Previously the presentation of such behaviours may have been attributed to having an ID, a practice known as diagnostic overshadowing (Barr and Gates, 2019).

Pamela talked about her own criminal behaviour.

*"I have been displaying the wrong kind of behaviour...the kind of behaviour that broke the law, as far as was to do this to anyone or others, I don't really want to say very much about the name of it, but I was breaking the law, and got into trouble for it ...I tell them all about the horrific things that have happened to me, I have had in the life some of these were horrendous ... ....I have flash backs I get angry and I cry and I cry in my room and I get nightmares... the doctor thought I was displaying rather wayward behaviour so he wrote Largactil on a prescription" (Pamela).*

This supports the point that prior to admission to a secure unit, women are 55% more likely to have experienced sexual abuse as opposed to 17.6% of men (Sahota *et al.*, 2010). Pamela described symptoms that relate to post-traumatic stress disorder (PTSD). The women had suffered trauma, although they did not recognise it as such. The survivorship shown in the narratives from Pamela and Penny suggests that they were confused and had difficulty surviving the abuse, resulting in them perpetrating abuse on others.

The women can see how their journey has impacted upon their life. Fish (2013) found that including the voices of women with ID can show positive attributes such as actively asserting their own identity as opposed to the role bestowed on them in

an institutional setting. In this research study the women asserted their identity in different forms, depending on how their journey had developed. Nevertheless, the women demonstrated resilience after some difficult family experiences and complex arrangements in their care.

*“...I said to [\*male nurse] I am not having her [\*female nurse] to my name and he said why not, and I said you have got to be joking...”* (Olivia).

In this extract Olivia described how she raised her objection to a particular female nurse who was allocated to support her. Equally, one of the women told of how she asserted her bi-sexual relationship:

*“I used to have good banter with him but him and [\*female HCA] were alright with me and [\*fellow patient] being in a relationship”* (Theresa).

Olivia and Theresa gave examples from episodes in their life when they have asserted their own identity, through objecting to a particular RN or asserting their sexual identity. This point is noteworthy since the literature refers to the ease with which women with an ID can discuss sexual identity, whereas men feel stigmatised (Abbott, 2013).

Trauma is important to this study since many of the participants referred to the issue throughout the semi-structured interviews. The way the participants related to trauma told the researcher there was something important to explore in the data. The nurses acknowledged that the women had suffered abuse, were vulnerable and traumatised.

*“all of my ladies have had some form of trauma in their lives”* (Nurse Amy).

*“All of our ladies that we look after have had some form of trauma in their lives”* (Nurse Charlotte).

The nurses recognised the trauma the women had experienced in their lives, through losing children, being abused, being part of chaotic families, lifestyle or being victimised because of their vulnerabilities.

*“Trauma is a huge thing with the males as well but more so with the females... most of them in some shape or form ...”* (Nurse Julie)

Nurse Julie compared the trauma experienced by the women to be worse than their male counterparts, although experience of Trauma is not gender specific (Muskett, 2014)

*“...whether that being kind of trauma of them losing family members or some kind of abuse most people had experienced it in one shape or form” (Nurse Julie).*

Understanding the trauma suffered by the women was therefore informing how the nurses were currently supporting the women by becoming a trauma informed service.

### **Dealing with disclosures**

The nurses said that disclosing abuse and the legal aftermath were important aspects to promoting the women's identity. They provided the women with security and reassurance of protection from an abuser, as well as openness and trust to be able to discuss or disclose abuse without reprisal or judgement.

*“...a young girl whose behaviour was incredibly disturbed and she would require restraint which was fine we could deal with that but she had quite long hair and of course whenever you were trying to talk to her to calm her down everyone thought you do things for the best they used to move the hair out of her face so sweep it off her face so you could see her and respond to her and she used to react incredibly honestly it used to freak her out completely and it took so long for her to trust us and say when she had been abused that was what the gentleman used to do was wipe the hair off her face. OMG we were devastated because we said you are trying your best with this young girl to try and calm her down and we were making it worse so things like that” (Nurse Ivy).*

Some of the women displayed behaviour to be secluded, and then used the time to disclose trauma:

*“... she made an incident to get us down to the de-escalation room so she could talk some more about it” (Nurse Julie).*

This is an important illustration of how the nurse/patient relationship was therapeutic. It seemed this encounter enabled disclosure of abuse that she had perhaps attempted to raise in the past.

*“I had a lot of disclosures so people disclosing stuff to me of abuse, and you have to be there to listen and not judge so I think that... she would self-harm and she disclosed that she had been sexually assaulted when she was 15 years old but it was bit by bit she never told me everything together” (Nurse Julie).*

The nurse revealed here how she created a trusting relationship and enabled the woman to tell her story at her own pace, building on small amounts of trust. This meant the woman could equally build up to tell her whole story. Disclosing abuse can be problematic for women with an ID, and staff working in women’s secure service do not always know how to respond to disclosures of distressing experiences, including rape (Philips, 2013).

Recently there has been a shift in society on disclosing abuse, through education, accessing information and social media. Over time the women’s secure service has also developed.

*“I think we have moved on in society so much over the last 20 years, people understand those things now the whole thing around abuse, domestic violence and a women’s service now it would be so different because of all of those things” (Nurse Ivy).*

It is known that women have been unable to protect themselves or articulate their abuse, as reported in the Saville Inquiry (Operation Yewtree) and subsequent reports of abuse by high profile celebrities (#MeToo). The nurses were passionate on this issue.

*“We have some very intelligent women in this country and in society who cannot protect themselves from violence and abuse and cannot articulate that so how do we expect someone with a learning disability to be able to do that which we do so we have to think outside the box I suppose as to how we can get people into that and to protect themselves” (Nurse Ivy).*

Ending assumptions that the women can protect themselves from trauma, acknowledging the trauma and challenging the injustices the women have suffered is important to developing care and opposing unhelpful assumptions.

Survivorship is underreported in ID services, although the notion of resilience is emerging (Peckham *et al.*, 2007). The recovery model largely utilised in mental health services is graduating into ID services (Slade *et al.*, 2014). Momentum is gathering to change policy and question the injustices that people with an ID have experienced (Northway, 2017). The women in this study were seeking support from the nurses who were giving the support in the best way they could, however critical thinking is still needed from a strategic level.

#### 6.A.2.3 Exploitation

Here one of the women (Margaret) described a time in her life when she was living in the community prior to being admitted to the ward. Her narrative shows how she was vulnerable, bullied and exploited. Unfortunately, the term 'mate crime' is increasing and occurs where a person with disabilities is befriended then becomes the victim of a crime, a situation which has resulted in murder (Thomas, 2012). Similarly, the likelihood of a vulnerable adult experiencing a 'hate' crime is significant and substantially increased when the person has mental health problems or cognitive impairments (Emerson and Roulstone, 2014). An adult with an ID living in the community is vulnerable and at risk of being a victim of a crime, in particular a hate crime (Barr and Gates, 2019). The prevalence and nature of disability hate crime was explored in a study that found that half of the respondents had experienced victimisation of some sort (Richardson *et al.*, 2016). Unfortunately, this illustrates that living in the community is not without difficulties, and the vulnerability of the women left them open to abuse from others.

*“I used to be in the community I had a flat and they cut all the repairs out, so I was hanging around with gay people because I am gay myself, they were horrible” (Margaret).*

For Margaret, perhaps entering into same sex relationships was a way of fitting in with the community.

*“I had my own flat in [\*] but it didn’t work out and I got into trouble with the police and my arson problem and drink and drug problem and mixing with the wrong crowd of people, it wasn’t my scene really I just got very poorly” (Margaret).*

Margaret’s account of her experience in the community was negative and gives the impression that those people who were horrible to her may not have been interested in her at all. Instead, it was merely a façade to abuse a vulnerable woman with ID living in the community without support.

#### *6.A.2.4 Multiple assessments and co-morbidity*

This sub-theme shows that there was evidence of comorbidity in the women’s condition, originating from the significant amount of assessments they had persevered through as part of their diagnosis and subsequent assessments. This included physical health assessments for illnesses such as epilepsy, women’s health reviews and medication assessments, including monitoring and mitigating any side effects. The current literature indicates that those with a mild ID have worse health outcomes than the general population and are more prone to exposure to social determinants of poor health (Emerson, 2011).

*“even when I was in the wheelchair, they just let them go and they wouldn’t go so that was when they put an injection into my kneecap and unlock it, in surgery though because I was a child. This has been going on from the age of 12 with the physical health” (Olivia).*

This participant described her experiences from childhood of the treatment she received for physical disabilities, and how it was dismissed even though she suffered from a chronic condition.

*“The physical health started to ween off and then my mental health started going so the physical health went and the mental health come but then sometimes when my mental health is really bad my physical health interlinks so if I am really distressed or really worried I will get pains or I will feel like I have something wrong with my appendix or anything, it feels like a proper stamping pain like that and you are just in so much pain but there is no real cause for it when you have tests done and stuff ” (Olivia).*

Here (Olivia) was powerfully describing the interaction between her mental and physical health, and the difficulties of living with an ID and mental health can be found in current research (Sutton and Gates, 2020).

The impact of enduring many physical assessments suggests the women were more likely have co-existing conditions and predisposed to poorer health outcomes, which may have resulted in diagnostic overshadowing. Although, the women were focussed on engaging in DBT sessions to accomplish discharge. The women told of the numerous assessments they had experienced in their journey, which were often unnecessary and invasive.

*“so, I was in [\*] Hospital like as an inpatient to get assessed to see if I had epilepsy and stuff like that and I didn’t but they still put me on these purple tablets but they were like big tablets so I wasn’t epileptic or anything like that and I didn’t show that I was having fits or anything or seizures or anything”. (Lauren).*

This participant was prescribed an anti-epileptic medication despite not having epilepsy. Lauren added to this experience:



*“...and people from children’s came to assess me at home and said you need to come in so that was when I got took there... (secure children’s ward)”*  
(Lauren).

This suggests that a more holistic, person-centred approach would lend itself to a seamless service and benefit the women in the sense of reducing negative engagement with services.

The women described aspects of their condition in terms of medical comorbidities, and how they had undergone multiple assessments and subsequent diagnoses. Mild learning disability, mental health conversion syndrome and paranoia were diagnoses relayed by the women. The women correlated their condition with low mental health and episodes of being unwell. They spoke about having co-existing conditions which included paranoid schizophrenia, drug addictions, self-harm and attempting suicide. Ribeiro *et al.*, (2015) found that over 62% of women with ID had multiple diagnoses and over 57% have schizophrenia. This supports the findings in that the women have higher levels of psychological distress, as opposed to criminogenic need, than their male counterparts (Sahota *et al.*, 2010). The impact of co-morbidity in secure settings affects the length of admission, discharge, and readmission.

*“I was quite poorly with it so I would have seizures, or I would pass out or meds wouldn’t agree with me because they would counteract with the side effects, so I was having all the side effects to every single medication and I was in like general hospitals all of the time”* (Olivia).

The women articulated their gynaecological ailments openly:

*“I do have cysts, so I get cysts in the ovaries and sometimes they say that it pops before you get to scan because it takes a while for them to see through, but you can still see the dark patch where it has been. They weren’t sure if I had polycystic ovaries, but they will haven’t looked into that because I haven’t had any more pain for about nine months so hopefully it has fizzled out because I really want to have children in the future and stuff like that and if*

*you have polycystic ovaries, it is hard because they have to remove one of them” (Olivia).*

Here Olivia did not provide details of any family planning advice given to her as a consequence of having polycystic ovary syndrome. Even though she had expressed a desire to have children, the presence of the condition may render her unable to conceive.

Reflections were also made on the reasons for admission, in that:

*“not because of alcohol more pointed towards wanting to end my life... I started hearing voices and I became distressed, self-harm and anything that I could swallow and get my hands on I would... I wanted to be with him... (deceased friend)” (Olivia).*

*“I started when I was eighteen and I was really really poorly, and I had anorexia when I was in [\*] hospital, then when I got my period then I got better” (Theresa).*

The women were not emotive when they portrayed their stories, and they were not angry or bitter as would be expected of the seriousness of the experiences they have endured. The women demonstrated a significant level of indifference when they spoke of having multiple, complex physical and mental conditions. Instead, this was accepted as being a matter of fact, whilst multiple complex mental/physical health were similarly viewed as an expected fact of their life. This is an illustration of the women acknowledging what is already known in the literature, in that they will experience health inequalities and multi-morbidity (Barnett *et al.*, 2012; Emerson *et al.*, 2006), and that they have an increased risk of psychiatric disorders (Tural Hesapcioglu *et al.*, 2019). The women are naively unaware of the fact that statistically they are more likely to die younger by thirty years than women without an ID (Cooper *et al.*, 2015).

#### *6.A.2.5 Criminal behaviour*

Crimes the women had committed included arson, illicit substance use, child abuse and offences against the person. As expected, the natural course of justice was

followed in terms of arrest and detainment. However, the criminal liaison and diversion service had been applied in some instances, as set out in the Bradley report (2009). This meant that the women were assessed, and the presence of an ID triggered a diversion away from the CJS, away from mainstream legal processes and into secure health services as opposed to prison.

Yet the diversion service was not applied in all the circumstances.

*“I set fire to the petrol station in ... and I went straight from there to... prison and from that prison to here. It has been about 14 or 15 months that I have been here now” (Margaret).*

The women were reluctant to have the contact with the CJS and were certain in their decision to avoid court appearances. This is synonymous with the literature in relation to offences, where an audit of a pathway in secure female ID services found that 65% had past forensic histories, including assaults, and 21% displayed challenging behaviours that had not reached the court’s attention (Beber, 2012). The Corston Report (2007) set out how the CJS should support women with particular vulnerabilities. Corston 10 Years On (2017) revealed there was still work to be done.

Criminal activity prior to admission to secure services is less prevalent in women than in men with ID (Sonata *et al.*, 2018), therefore it is interesting to note here that the women refer to the crimes they have committed candidly.

*“...and I turned on my mam with a knife, so my mam thought I was going to kill her because I was literally unwell at the time” (Lauren).*

This participant attributes her crimes to being ‘poorly’ and was thus unaware of their actions.

Penny talked about how she abused children:

*“...I was doing bad things to kids and all of this” (Penny)*

This supports what is reported in the literature in terms of an abused child becoming a perpetrator of abuse and having comprehensive criminogenic needs (Hollin and Palmer, 2006). Meanwhile, Olivia detailed how she committed arson.

*“...keep off the drink and the drugs and make friends with the right people and not run away or set fire to things...” (Olivia).*

Whilst there is substantial literature regarding men with ID and fire setting, there is limited work of this nature related to women.

*“My behaviours, I have been displaying the wrong kind of behaviour...the kind of behaviour that broke the law, as far as was to do this to anyone or others, I don't really want to say very much about the name of it, but I was breaking the law, and got into trouble for it” (Pamela).*

The women could articulate their crimes indifferently, whilst also being as honest as they could manage. The women were accepting of their crimes and able to ask others to do the same. It appears this was possible for the nurses, in that they have not condoned the crimes the women have committed but accepted the situation, as the nurses did not discuss the women's crimes at any point.

This theme shows how the women see their criminal self, illustrating that they have a level of insight into their life events and the incidents they have experienced so far. The women have undergone horrendous life events but have accepted and come to terms with this in a way that illustrates survivorship through their own resilience.

#### *6.A.2.6 Instinctive characteristics – you just know*

The nurses spoke of the type of person and the characteristics required to be a RN working in female SS, although they were clear in the belief that ‘you just know’. The nurses did not believe that reading literature or attending university necessarily provided them with the characteristics to do the job, but instead their view was one of intuition. They know the women, work holistically and can respond naturally.

*“its an experiential thing, something you learn not so much through the literature, I think you either get it or you don’t ...I think it’s a personal thing I always felt more passionately about the women I didn’t realise...until it was taken away from me, until it closed but mind, when I wasn’t in there phew, I wasn’t as stressed but that goes away... I felt more passionate about the women because of the lack of interest, I thought it was the service that time forgot” (Nurse Grace).*

*“my time working with the ladies particularly the last nine years I worked with them, it changed me as a person, because I saw things differently” (Margaret).*

The nurses said that they had instinctive characteristics, although they recognised the importance of becoming a registered nurse as a fundamental aspect to being able to do the job.

*“the more I think working with the women I was older I had a child of my own I was parenting these ladies, it’s that basic nurture they didn’t have sometimes I was their nurse, their mam and sometimes even their dad I knew the difference of what was needed...I really enjoyed it and didn’t realise how much until it was taken away” (Nurse Grace).*

Finally, the nurses were dedicated, committed and passionate about their job. They described their job as a vocation.

*“I just want to make a difference really...I think everybody knows that you don’t come into nursing for the money” (Nurse Bella).*

The semi-structured interviews provided an opportunity for the nurses to demonstrate their passion about a job they are wholeheartedly proud of.

#### 6.A.2.7 Endearment

The women had committed crimes, had an ID, had challenging behaviour and posed a risk to themselves and society. However, this was juxtaposed by the behaviour and practices of the nurses around the women, which was positive, caring, supportive, nurturing and maternalistic. They often used terms of endearment when they referred to the women.

The inclusion criteria in the research study for the nurses was discussed in section 4.2.2 and did not exclude male nurses. Incidentally, however, the nurses in this research study were all female. Those nurses said they could relate more positively to the women because of who they were.

*“the women are complex and not straightforward, but I am not either”* (Nurse Julie).

*“I think for me, with the females I can relate better to them because I am one”* (Nurse Amy).

*“...with women it was more personal I don’t know if it was because I am a woman”* (Nurse Grace).

Thus, they were able to rationalise the complexities of the women through relating it to their own complexities.

#### *6.A.2.8 Possession*

Throughout the semi-structured interviews, the nurses used a singular possessive pronoun, such as ‘my ladies’ and ‘ours’, when they referred to the women, staff, and ward. Describing the women and staff in this way gave a sense of possession and belonging. They referred to the women who had been on the ward long term collectively as *“our ladies”* (Nurse Charlotte, Nurse Karen, Nurse Natasha). Others stated, *“I have ladies with autism, PD, all have an ID”* (Nurse Amy) or *“All of our ladies that we look after on the wards ...”* (Nurse Charlotte). However, referring to the women as ‘my ladies’ may lead to treating them as childlike, disabled, dehumanising (when described as a generalised group).

*“all of my ladies... whether it will work with my ladies I don’t know”* (Nurse Amy).

Using a possessive pronoun may lead to a power imbalance in relation to the women and a possible hierarchy when referring to the staff:

*“our ward...it’s difficult for our ladies”* (Nurse Bella)

*“a lot of our ladies are diagnosed ...”* (Nurse Charlotte)

*“communication is a key thing for our ladies”* (Nurse Davina)

*“...whereas my ward was ...”* (Nurse Emma)

This narrative can be likened to how a person may refer overprotectively to a family member, in a sense of belonging, as in ‘our kid’, ‘our lass’ or ‘our [Julie]’.

Similarly, the nurses referred to nursing staff in a possessive way:

*“... I’ve got a lot of long-standing staff, both HCAs and nurses, I’ve got two of my nurses have worked on the ward for ten years, I’ve also got HCAs who’ve been ten years plus”* (Nurse Amy).

*“...has trained all my staff to look at how we go forward with (TIC)”* (Nurse Amy).

*“...I think a lot of my staff get that job satisfaction”* (Nurse Amy).

*“...I have had supervision on Tuesday with one of my staff team...”* (Nurse Bella).

Referring to women as a homogenous group in a possessive sense suggests a perception of belonging, in that the women belonged to the nurses. This may in turn lead to the nurses not seeing the women as individuals, but more as a subject to the treatment of others which is suggestive of non-individualised care.

The women who had previously lived independently in the community and were re-admitted to the SS were vulnerable and had been exploited. A lack of services and input from professionals left the women to be victims of hate/mate crime. In some cases, this resulted in a change of identity including sexual orientation to fit in, nonetheless resulted in them being targeted by abusers.

## PART B: Experiences of the Present

### 6.B.1 Current Experience

This theme centres around what participants said about their current experience, particularly their living and working situation. The sub-themes within the overarching themes are daily living in the ward, liberty, incidents, independent living, violence, and aggression, and friendly staff/saying the right thing.

This theme shows how the women made comparisons between their experience in the children's service to that of adult services. The nurses spoke of their views on doing the job, particularly how they saw the important aspects of working as an RNLD in female SS. This included what was involved in the role, what it meant to their career, and the attributes and qualities needed to be able to do the job. The innate characteristics they had and what skills they were taught or learnt from others to be able to do the job was also discussed.

#### *6.B.1.1 Daily living – in the ward*

There was a structured daily routine in the ward on weekdays, which began early in the morning, to extensively plan the weekdays. Weekends were noted to be more relaxed.

*"I get up about 7.55 but I just stay in bed at the weekends or sometimes I go for a walk on a Sunday if it is a nice day..."* (Margaret).

There were social activities held on the hospital site available to all wards.

*"...and you went to the disco, it was inside the hospital it was in \*...on a Thursday night..."* (Theresa).

Daily living activities included the choice of attending a session in or outside the ward. The women accessed the activity centre and noted that keeping busy helped



eliminate boredom. Specific therapies were also referred to as being helpful. The women were allocated a specified amount of free time to do whatever they wanted. This was referred to by the women and the nurses as ‘*ad hoc*’, and while this seemed in principle to be an incentive for the women, it was noted that it was only for short periods of time:

*“...I only have forty-five minutes...”* (Margaret).

Day-to-day living was not straightforward for some of the women, and one participant described how she lived in a ward alone and was secluded for significant lengths of time.

*“It was awful...but not all the time, not this one I like this one... in seclusion for 8 weeks the seclusion made me very very angry... on [\*] ward in this hospital...I lived there on my own I had the ward all to myself... this helped me... I used to live on the ward by myself...”* (Ruby).

Ruby was reflecting on her experience and seeing how living in this way has helped her. Particularly since at the time of the semi-structured interview Ruby was due to be imminently discharged to the community. Research has found that those in secure hospitals understood least restrictive practices as restraint, seclusion and forced medication (Tomlin *et al.*, 2020).

Olivia compared her daily experiences in children’s secure to adult secure service.

*“...it is boring to be honest you do the same shit day in and day out... I would prefer if they put more fitness classes on and more on an afternoon because they normally tend to do it on a morning so from 9 until 11...I do prefer like in children’s I used to go 6 until 7 to the gym every night and also because I sometimes get hyper on a night-time and sometimes it helps me to chill out and not be so hyperactive...it lifts your mood when you do exercise... to your self-esteem...”* (Olivia).

This participant saw her experience in children’s service as positive, as she had more freedom and acquired more things on children’s wards, whereas in the adults’

ward things were taken away. Difficulties with transitioning from children to adult services is noted in the literature as a difficult process that lacks information sharing and access to information, while also featuring poor planning (Bhaumik *et al.*, 2011).

#### *6.B.1.2 Liberty, independence and security*

The women related their value of independence in terms of whether they held a key and had access to personal items.

*“On this ward not all the doors are locked, the kitchen and bedrooms have keys so that we have our own room I have my own things I have a sense of independence, I have clothes, toiletries television some CDs one or two books and things like that...”* (Penny).

This participant accepted to some degree they had lost their liberty and security for treatment purposes, and that this was a necessary part of a secure ward. Personal care was a significant factor and earning the right to have a contraband key meant the women had increased choice and independence.

Negative experiences were related to restrictions placed upon the women, specifically observations, restraints, seclusion, leave and lack of freedom. Everything was locked and the participants had to live by rules and regulations.

*“... it was six months lack of freedom...”* (Steph)

*“I have a contraband key and a key for the bedroom and a key for sharps so I can have a shave all the time, I can shave my beard any time I want”*

(Margaret)

Here Margaret told how she had earned independence and was trusted with access to dangerous, harmful items that can be used as weapons. She was allowed to attend to her own personal care when she wants to and not at the discretion of others.

Margaret is a mature lady and has had her own home and been in prison. This level of independence is important to her, as it allows her to show how she can accept the responsibility and use it appropriately.

However, some questioned the length of time they had spent in SS.

*“I was on section 3 which is three independent doctors to say you have to be in hospital or when you can get out... a psychiatrist said to me you will be in for five years I was in four and a half so I got half a year off my sentence the maximum is eight years then they have to move you on but there is one patient who has been in there eight years before (this hospital)...when they said five years...I said what are you talking about...I haven't done anything wrong it's my vulnerabilities...it's in my genes, I did four and a half” (Steph).*

Indeed, Steph was right to question this length of time and, moreover, to also question the professional who issued her with a sentence. The problem of challenging detention and arbitrary decisions is well documented in the literature (Bournewood case; MCA 2005).

#### *6.B.1.3 Treatment – Evidence-based practice*

Participants in the research who were currently working in the secure service told how they are implementing new ways of working, one of which is the introduction of trauma informed care (TIC). Research has been conducted to support the inclusion of research in learning disability nurse education, particularly that which is relevant from clinical practice and related to field-specific programmes (Northway *et al.*, 2015), thus demonstrating that evidenced-based practice is current.

#### **Trauma informed care**

TIC is an emerging concept which acknowledges the lasting effects of trauma, and nurses are ideally situated to further this approach to nursing practice (Stokes *et al.*, 2017).

*“...we are also piloting trauma informed care... previously it was seen as psychology focussed intervention, where they would go and speak in a private*

*room really, where they talk privately about things that had happened to them, historical events...” (Nurse Bella)*

It is suggested that ‘universal trauma precautions’ are taken to all patients (Elliot *et al.*, 2005) to minimise any risk of retraumatising a patient whilst admitted to a secure service. However, what is also understood from the literature is that as many as 90% of those receiving treatment for substance abuse or mental illness who have had contact with CJS were subjected to significant emotional, physical, or sexual abuse in childhood (Talbot *et al.*, 2011; Wheeler *et al.*, 2005). This approach acknowledges trauma suffered by the women and focusses on engagement and participation via structured sessions taking place throughout the day at key times.

*“As a service it has previously focussed on diagnosis looking at a woman who has a PD then that’s it...TIC gives us as a team a different perspective...a different way of supporting our patients, but hopefully with the core sessions it brings that engagement ... a homely atmosphere helps” (Nurse Amy).*

The nurses in the research were adopting a holistic person-centred approach to individual women, and there was evidence in the data that the nurses were accepting the concept of parity of esteem.

The nurses acknowledged when the women were upset, for example after speaking with family or upset at birthdays/significant dates. Hall *et al.*, (2016) suggested that nurses are puzzled by ambiguous descriptions and have difficulty in the application of TIC into daily clinical practice. The data from this research study shows the nurses have are fully conversant and confident in the language and implementation of TIC. Extensive staff training and support on working with trauma was evident from the data. Once TIC is embedded into the women’s service there are plans to implement across male ID SS. TIC is incentive-based, with extra outings if a patient engages, and involves altering unreceptive bleak wards into homely and welcoming environments (Azeem *et al.*, 2011).

*“We would have rugs and fluffy cushions...try and make their bedrooms nice so they would have matching curtains with their duvet covers just to try and make it as personalised as we possibly could. We can’t take any glass*

*framed pictures in because we are a secure unit so it was how can we get around this, so we looked at Perspex picture frames” (Nurse Hannah).*

A homely environment was aimed for by the nurses who previously worked in the secure female ID service, and they talked about trying to make the ward less hostile and more welcoming.

*“It [TIC] is a new way of working but I think we are lucky with high staff ratio...and a homely environment helps” (Nurse Charlotte).*

The nurses were attempting to create a homely environment for the women in the ward, which is synonymous with the current literature relating to implementing TIC, implementing trauma precautions, and reducing the possibility of retraumatising the women (Muskett, 2014).

*“...I think they struggle...with their free...unoccupied kind of time, boredom is a trigger...for aggression and agitations...keeping them going and occupied was a key” (Nurse Julie).*

Introducing trauma informed care brings structure and core sessions to attend. The aim of core sessions is engagement and participation.

*“...the nursing...and patient team decided the times because they fitted in with the other activities, but they also fitted with lunch and when patients become bored it would be those significant periods when their behaviours would escalate” (Nurse Bella).*

*“...what we find at the moment is when patients are bored, and they haven’t got things to do we are seeing an increased risk with behaviours...” (Nurse Amy).*

*“Introducing TIC gives the team a different perspective, a different way of supporting our patients, you look at flash points in the day, so we chose different times in the day to do the sessions where we felt were most likely patients’ mood to decrease but also settled, bringing someone back to baseline during those sessions” (Nurse Amy).*

*“It is a proactive way of working rather than reactive” (Nurse Bella).*

This approach enables consistency, structure, and boundaries, yet gives autonomy to attend or not. It gives support when a woman is upset, which could be triggered by a significant date or after speaking with family members.

### **Care zoning**

Care zoning is an intervention where levels of risk are identified and managed through levels/zoning, which has been found to improve mental state and clinical risk documentation (Mullen *et al.*, 2013). The nurses talked about implementing care zoning in the ward in a style that was adapted from another Trust, and in this approach the women decided on the colours. RNs give responsibility to HCAs to then review the colours. This approach values the input of the HCA in supporting the women on the 'shop floor'.

*"...gives HCA's the autonomy to make a decision... if they feel that somebody has deteriorated and would need the colour reviewing that is done with the HCA and the nurse and people's colours can change every hour or every minute if needed but it is nothing that would include the MDT, so it is putting a bit of the decision making back into the nurses where I think we have lost"*  
(Nurse Bella).

The positive outcome of this approach is in the fact that since implementing care zoning none of the women on the ward have been subject to constant observations.

### **Dialectical behaviour therapy and radically open dialectical behaviour therapy**

Dialectical behaviour therapy (DBT) and radically open dialectical behaviour therapy (RODBT) are also treatment options. DBT has been found to be effective within secure ID populations (Morrissey and Ingamels, 2011). Meanwhile, RODBT is usually quite suitable for people with autism since it is a treatment for over-controlled personality, a condition which is common in depression (Lynch, 2018).

*"... some of the women starting on RODBT soon"* (Nurse Amy).

The nurses acknowledged the level of work that is involved to implement DBT and have attended further training in DBT awareness skills.

*“DBT is a programme that we run, a lot of time during first admission is preparation to attend the courses, because it takes a lot of focus, the ability to engage in a group setting, initially ...they don’t have that ability to tolerate others in a group or know when it’s time to listen, this person talking it’s my turn to listen, the social cues, sometimes it’s the first six to twelve months its preparation work just to enable them to engage in an intervention, which can be why we end up having ladies for longer, but if you are going to do something we need to do it right, it does take a lot of preparation work” (Nurse Charlotte).*

On the other hand, the women who are progressing through DBT as part of their treatment described the process as follows:

*“I say f\*\*\*\*\*g shit sometimes and stuff like that and I just say I want to be home and be with my mam and then I start saying positive statements to myself because at the minute I am doing DBT and the staff are saying that they see benefits in that for me but I don’t know where because I don’t know if it is helping at the moment and they have said that is normal because when you are doing something you don’t realise what the change is...” (Olivia).*

Although Olivia was unable to see the benefits of DBT in this narrative, she went further in the interview to describe in more detail her experience of DBT.

*“...obviously, I am doing a more difficult one it is more than trauma with me...it is crisis, coping and crisis, but it is more trauma but there is some crisis like being on a bridge...you can’t really say that in a group because it might upset the other patients but then they say you have to be open in a group but then some things you can’t be. They always say that you have to be open and give your best opinions in groups and sometimes you are like no it might distress them or how would that make them feel knowing that someone else is feeling like that because that is the way that I have felt before when someone else has said it and that is the way I have gone back and felt so that is why I don’t do it because I know how it feels. They always say you*

*should always give it your best ultimate shot, but I do in other ways I just won't say the stuff that I have done myself and my crisis and stuff because I don't feel that it is appropriate to say in a group in front of the patients" (Olivia).*

However, Steph could quickly see the benefits of DBT for her:

*"to shorten the time sentence, you can ask for a tribunal within the first six months after that then its yearly after that then they said you need to do the DBT because I did it and I flew through it..." (Steph).*

Here, Steph is talking about her experiences of DBT and how attending this therapy helped her demonstrate to the tribunal she can engage in treatment, ultimately to achieve her goal of discharge. Although, it is not known if Steph engaged with the treatment because of a tribunal requirement, or because she wanted treatment. Having said that, Steph is now living in her own home in the community.

There appears to be a menu of treatment options, allowing for ongoing testing of new and emerging models of intervention to achieve the best outcomes for the women. It seems clear that the range of treatment options available are person-centred in approach. The nurses saw the women through a holistic lens and the identity of the women was important to them, referring to the women using a possessive tense showed the nurses to be caring and compassionate. The nurses also displayed certain attributes, including anti-discriminatory practice. Although is important to acknowledge this is a significant attribute for a nurse, the attitudes, and perceptions of staff outside the female SS differed on this, viewing the women as dangerous and the service as a workplace to avoid.

The women talked about their diagnosis, treatment, and legal requirements in a knowledgeable and informed way. They demonstrated knowledge of their own situation and their peers in relation to detention and Mental Health Act restrictions. Whilst the correct words were used to describe these facets to their identity, it remains unclear if they had actual knowledge. The question which emerges was



whether their knowledge was acquired through studies, read about, discussed or was it in fact a rehearsed rhetoric.

Trauma was a significant issue in the identity of the women, as they had often experienced episodes in their life when they had been abused or became an abuser. The women had undoubtedly experienced trauma in their lives and the nurses acknowledged that fact. The acknowledgement of this enabled treatment to address the impact of the trauma, in terms of implementing trauma informed care (TIC). Furthermore, a homely environment is important for TIC and the nurses currently working in the service are striving for that. It is also interesting that the nurses who worked in the service years ago strived for that. However, none of the participants referred to post-traumatic stress disorder. Implementing the model of TIC in women's SS is innovative in itself, and moreover the plans to roll this into male services is revolutionary, since it is usually the other way round.

#### *6.B.1.4 Incidents*

The women acknowledged the disadvantages of communal living, and those women currently living in the ward noted that a good day was when everyone was happy, and when incidents happened everyone became unhappy.

*"A good day is everybody is getting on with it and just doing their own thing. Sometimes there can be bad days and sometimes people are shouting but it is not on our side it is normally on the other side...The side that I am on is very quiet there is only 3 of us on that ward and on the other side there are 5 patients and sometimes they can be .....I am on the better side sort of thing".*  
(Penny).

The women reported on how the occurrence of incidents affected them in both the short and long term, although there was a decrease in incidents where the women had accessed dialectical behaviour therapy (DBT).

*"I haven't had any major incidents for ages, I swear the odd time and I shout the odd time but that is about it, I swear and I shout but not really shouting at*

*anyone at all, not even to the voices because I don't even hear them anymore, I do but they are not ..... I say f\*\*\*\*\*g shit sometimes and stuff like that and I just say I want to be home and be with my mam and then I start saying positive statements to myself because at the minute I am doing DBT..."* (Olivia).

The evidence supports this in so far as Brown *et al.*, (2013) found that DBT has potential as an effective intervention for people with ID, and adapted DBT has been shown to be effective in managing aggression and self-harm (Morrissey and Ingamells, 2011), although the latter study focussed on male populations in high secure settings. Meanwhile, it is reported elsewhere that organisations may have robust systems to respond to incidents, yet the focus should shift to understanding the reasons and more preventative strategies should be explored (Lovell *et al.*, 2015).

#### *6.B.1.5 Independent living*

There were three of the women who had previously been in SS who were now being supported to live in the community. Speaking candidly and fondly of their experience in the secure wards, the women appreciated living in the community and valued the current level of independence at this point in their life. The women were resettled into the community post-transforming care agenda (Bubb, 2014) and seemed to cherish living on their own, albeit with staff support.

It is accepted that transition from education to employment is difficult for people with ID, and it is notably more difficult for women with ID as they receive less careers advice and men with ID are supported with placements while women with ID are more likely to be placed in sheltered workshops (Fasching, 2013; Fasching and Mursec, 2010). However, Steph explained how she had exceeded what is expected from the literature:

*"I've been to work today in [local charity shop] I love it I work there on a Monday because I am busy every other day and I am busy, and I will be*

*knackered tomorrow I am in a band and we are playing at (Local Further Education College)” (Steph).*

*“I have had my flat here four years or for five years, yes between four and five years and before that I was on [\*ward] in [\*hospital] I am 31 years old now, I was on the ward for 8 years, it was a high secure ward, before that I was in [\*] youth offending prison until I was eighteen, yes then from there on to [\*] the ward, I was in [\*] hospital I did look round [\*] hospital I was in [\*] hospital, when I was seventeen, so I went to [\*] youth offending, but I wasn’t there for very long then to [\*] hospital then to [\*] from seventeen to eighteen then I was transferred to [\*] hospital where I was in the ward for 8 years so it was [\*] hospital then [\*] young offenders then to [\*] hospital and before that it was home...”(Theresa)*

*“I was transitioning (to community) since the 13<sup>th</sup> of December last year 2018 and I moved here into this flat on my birthday, which was 28 January got my boyfriend and my job its voluntary but it’s a job and I am working and ... I was speaking to me friend like me boss me mam was saying to her that once I get down to fifteen stone, I can go horse riding with her sister does it I am busy but I have offered my help when I’m not at work and when I’m done at Slimming World” (Steph).*

The women living in the community described their daily living as fulfilled, narrating about the power and control that was placed over them when they resided in the secure ward. Paradoxically one participant, when living in her own flat, voluntarily asked the support staff to keep her bank card to help her save up for home comforts for her flat. The participant here perpetuated the power-and-control concept but shifting the power and control to herself over the nurses.

*“I’ve paid for everything here in my house, it’s all from Next, it’s all good stuff... you had your own bedroom [on the ward] and you could choose your own bedding, but it wasn’t the same and you had a hard mattress... I have given my savings card to the staff because I want to save up...I want a new jacket, a new leather jacket for the winter” (Theresa).*

Here Theresa showed how she has embraced her independence in community living by choosing and buying her own possessions, comparing it to living on the ward. However, this participant utilised the staff to her advantage by enlisting them to help her to save up, voluntarily handing over her bank card. This is an innovative approach to managing finances by a person with an ID. If the opposite were the case specifically, the staff were controlling the finances of the women, this would amount to a deprivation of liberty (Mental Capacity Act, 2005).

The women in this study want to have independence, to live in their own home, opportunities for employment and to exercise their right to a private and family life. Unfortunately, the presence of having an ID is an additional complexity in this challenge. When considering this possibility for the women it is important to look at the current evidence. Women with an ID were noted to have low recidivism in comparison to men, apart from prostitution-related offences (Lindsay *et al.*, 2006). However, violent, and arson-related offences are prevalent in women and more likely to result in readmission to high SS, indicating that, overall, there are poorer outcomes for women with ID in SS (Sahota *et al.*, 2010). This suggests that the women, once resettled with the right support in place, will flourish, as have some of the participants in this research study.

#### *6.B.1.6 Violence and aggression*

At times, the nurses sustained injuries in carrying out their job as a result of violence and aggression displayed by the women in the ward.

*“...I thought I can’t handle their level of emotions, their level of aggression and how much support they require”* (Nurse Karen)

This bears out what is reported in the research, in that nurses working in ID settings are constantly exposed to workplace violence and are at a greater risk of facing this than any other field of nursing (Campbell, 2011).

*“Their identity is now they are in this hospital like they are a patient in hospital they are not a mother, not a sister or a daughter anymore they are here, and*

*they are fighting to try and gain their identity back and I think it is so hard”*  
(Nurse Hannah).

This furthers the research which states that RNs working in the field of ID are the greatest asset to an organisation and best placed to care for those with an ID (Campbell, 2011).

The nurses accepted the violence they had been subject to, rationalising it by blaming themselves, as it was a failure on their part in that they let it happen. This could be another reason why not all incidents are reported, whereas the literature states that it is because of professional issues and issues around zero tolerance (Lovell and Skellern, 2013).

*“you go home, and you are really angry and upset because you have been hurt, your pride is hurt because how have I been stupid enough that this has actually happened you know two cracking black eyes I had, and I went back in the next day and was like right that was yesterday today is a new day you go in and do whatever”* (Nurse Hannah).

The nurses showed resilience and survivorship, attributing the violence to the difficulties the women have experienced in their life, thus not taking it personally and carrying on with their job.

*“...If you are hurt and you are verbally abused or whatever you have to literally just think these people are unwell and have got difficulties, they are not doing this because you have done something they are doing this because of the circumstances that they are in, the life changes that have got going on and because they are genuinely scared and upset and they are lost really I think”* (Nurse Hannah).

Episodes of violence can be found within ID populations, with earlier statistics reporting prevalence varying between 10% to 40% (Emerson *et al.*, 2001; Grey *et al.*, 2010). Statistics reported from an NHS staff survey in England found that 37% of RNs and HCAs working in ID services had experienced aggression by a patient, relative or member of the public (Royal College Nursing, 2018). Lovell and Skellern, (2013) found that nurses are accustomed to and accepting of violent incidents.

#### 6.B.1.7 Friendly staff/saying and doing the right thing

The nurses stressed the importance of being happy and having a smile whilst doing their job, recognising small things that may otherwise seem trivial can and do make a meaningful difference to the women. Previous ways of working in SS prevented ward staff from being open with patients, as this practice was viewed as a measure to protect the privacy of staff in relation to the criminal behaviour of some patients. In practice this meant staff did not talk about families, children, or pets. However, the nurses in this research study were clear about being open with the women. Although the nurses were precise in their account of doing and saying the right thing to the women, good nurse attributes, as discussed in the literature, are creative and adaptive when responding to complex situations (Taua *et al.*, 2017). There was noteworthy reference made to how the nurses communicated with the women, often being jolly and motivational.

*“Just everyone to be happy, everyone to be happy, smiling...”* (Nurse Emma)

*“...if we can get the little things right then the big things sort of sorts themselves out* (Nurse Bella)

*“People smiling, people telling me they are happy, people just being alright”*  
(Nurse Amy)

Here the nurses accepted the similarities they had with the women were open about it:

*“we are all people, and they know, that people have got or had a parent, otherwise you wouldn’t be here, so for me it’s a safe subject for me to talk about I’m open about and, like I say, they quite like that...”* (Nurse Amy).

The literature supports the notion that RNLDs have a therapeutic relationship and can support people more effectively when they have a full history and background (Lovell and Skellern, 2020)

Saying the right thing to the women was important to the nurses:

*“the ladies we look after are very set in their ways at times, they are very used to certain responses, things that you say to them at times which can often be difficult”* (Nurse Charlotte).

Talking about what to say and what not to say, how to do the right thing and creating the right atmosphere involved constantly re-thinking every detail and interaction.

*“words that can be calm and words that can be seen as quite innocent can trigger a situation, so all these little key learning things”* (Nurse Charlotte)

This importance of keeping people motivated was also significant, as a number of the women had personality disorder, which means jealousy is a major issue.

*“patients will isolate themselves and return to their bedroom which they can then become destabilised...yes you need to constantly look over where you are what you are saying, what you are doing, if you are engaging with one patient, you often need to think about how that impacts on another patient”* (Nurse Charlotte).

Daily living in the secure service was described by the women as ‘not as bad’ and described by the nurses as ‘great when everyone is settled’. The unsettled nature occurs when incidents happen, particularly in terms of violence and aggression displayed. Interestingly there is one noted incident at a time, and rarely is there more than one of the women involved in a violent incident. Meanwhile the nurses described a settled ward when everyone is happy. Liberty is an important issue in the experience of the women in SS. The nurses are striving to secure freedom for the women, whereas some of the women were hesitant and accepted their loss of liberty as a fait accompli.

## 6.B.2 Relationships

The overarching theme of relationships demonstrates how significant the participants viewed this aspect of their lives. The sub-themes were peers, family, intimate/Sexual, and nurses. The relationships the women talked about included the

ones they had with their families, boyfriends/girlfriends, peers, and the nurses. Equally, the nurses talked about how they supported the women in their relationships.

#### 6.B.2.1 Peers

When the women spoke about their peers, they had extensive insight and knowledge about the Mental Health Act (MHA). They showed an understanding of the legal status and an appreciation of the detainment their peers were subjected to.

*“...some friends were on a section, section threes, and I’m a thirty-seven, and then one of the friends [\*] she was a thirty-seven and a forty-one, a restrictor... you can’t get out on leave, section three is just a treatment section, two is just treatment, its six months for a section and thirty-seven is a harder one...”* (Olivia).

The MHA (1983 as amended) provides the legal justification to detain and treat a person who is suffering from a mental disorder without their consent ([legislation.gov.uk](http://legislation.gov.uk)). Olivia was referring to different sections within the MHA, proving her level of insight into an intricate legal framework, which must be difficult for a person who has an ID.

Admissions to various wards enabled the women to meet countless peers, though transience between services did not always facilitate friendships to be maintained. The women told of how they were maintaining relationships formed with peers five years later.

*“I had good friends, [in the ward] \* was my best friend, it was \* and \* there was a few of them and \* and \* and \*, yes and \* he was on another ward in the hospital...I still keep in touch with them after five years, he is visiting me tonight he is my friend”* (Theresa).

Whilst the women formed relationships on the ward, they experienced difficulty in sustaining friendships.



*“I had loads of friends I used to have [\*] from my ward but I don’t know where she lives now, you lose touch, and the ward is closed now I might have kept in touch with some patients with text or phoning...” (Theresa).*

Being moved around the country across a wide geographical area was unhelpful to their relationships.

*“I was thinking they are going to start me from scratch in another setting and meet new people which I don’t really like...” (Olivia).*

People with ID aspire to having close relationships, and there are significant benefits for people with ID in forming and maintaining close relationships (Lafferty *et al.*, 2013). This was illustrated succinctly when one participant said, *“I like meeting new people but not in hospital”* (Olivia).

#### 6.B.2.2 Family

The women told of how much they valued families:

*“my best relationships... at home probably, not in here” (Olivia).*

But then again family composition was not straightforward:

*“...she had a really troubled life she had children who were all in the care system...they were really dreadful she had brothers and sisters who were all in the care system and you were just thinking OMG” (Nurse Hannah).*

Family dynamics included adoption, extended families, siblings, grandparents, being abused by a parent or assaulting a parent and a parent being admitted to the same ward. Relationships and contact with family was noted to be either dysfunctional or supportive.

*“... and on the Monday night my biological mother was admitted to the same place and my behaviour went downhill so that’s why I had to get moved to medium (SS)” (Steph).*

The dialogue between the women and the nurses about families was candid:

*“I think that’s important; you’ve got to be open and honest, there’s no point in fluffing things up I think that’s really important, and we aren’t always great at that” (Nurse Amy).*

It was seen as important to be truthful with the women, even though giving the women the facts can mean delivering bad news. RNLDs are notably adept at delivering bad news whilst maintaining therapeutic relationships.

The nurses told of how they reassured the women about their families, being candid by frankly telling the women the reality of their loss. Counteracted by arranging contact, gifts and visits, explains how the nurses were central in enabling the women to maintain family relationships.

*“We would just say look you know he is safe, you know he is warm, you know he is with your auntie so we know he is good and she would say yeah and we are going to ring him later so you can ring him in the morning and then we will have dinner and you can ring him later on and she would say ok then and then just keep remembering you are going to see him in x number of days’ time so then we will take some more presents down that you have bought and you can have that Christmas with him and that is as good as you can do” (Nurse Hannah).*

It was also seen as important to treat the women respectfully, accepting they are mothers and that they have the right to a family life regardless of what that entails. This is showing the depth in the level of the relationship between the women and the nurses. The inherent attributes of the nurses and how they can support the women in complex situations were also evident. As such, it was clear that there were natural skills and attributes in evidence in the role, and that there is a ‘type’ of person who becomes a RNLD (Genders and Brown, 2014).

The nurses said that the women were more sentimental than men (with an ID) about families.

*“.... you know women are sentimental towards family and things like that and I don't think the men are as much, you may get some who are, but I found the females that was the thing like have you got a sister yes, I have got a sister, have you got aunties, yes I have got aunties. You will also probably find the female staff will part with more personal information to the females, I have probably told them more about my family than I would the males because they were interested and they wanted to know, have you got any animals, have you got any family but I have never known any of the lads want to know about how is your sister, how is your grandma or if you go home because there was something wrong and they would say is everything is alright, is your family alright, they would ask you” (Nurse Hannah).*

The nurses were sharing with the women information about their own private lives away from the ward. This facet to the nurse-patient relationship demonstrates openness, not as a close friend but unquestionably as a close personal acquaintance.

Restrictions on spending time with family were imposed on the women in the ward, and logistical difficulties placed limitations on family contact due to living outside of the area, the availability of public transport and physical ill health of family members.

*“...just think about my dad at the moment because my dad has angina problems and heart problems and I have got my own problems at the moment like getting out here” (Margaret).*

Margaret was attempting to reconcile the failing health of her father and her own need to be discharged. The nurses were creative to facilitate contact with families for the women.

*“...they can also go on skype and keep in touch with their family which is why it is called KIT...that was the ethos behind it” (Nurse Amy).*

The nurses were creative in their approach to providing the women the right to family life.

*“...we did have some ladies who had children, children who were with their parents or had been taken into care...one of our ladies had to go to the social work office, which was unpleasant, so we arranged contact in a local park which was so much better for her...”* (Nurse Grace).

This included liaising with other agencies to work out what was best for the women to maintain contact with their families.

The women told of the incremental visits to the family home to maintain relationships with family members.

*“...I say f\*\*\*\*\*g shit sometimes and stuff like that and I just say I want to be home and be with my mam and then I start saying positive statements to myself because at the minute I am doing DBT, and the staff are saying that they see benefits”* (Olivia).

Parents were facilitated to reacquaint themselves with their daughter after being separated for several years.

*“My mam doesn’t even know what my favourite food is anymore and stuff like that...she doesn’t even know what my favourite food is and that’s just not right”* (Olivia).

The probability that such relationships would be positive is subject to question since fragmented relationships are common as a consequence of prolonged hospital admissions, and parents who have a child with an ID are at greater risk of stress and mental health challenges (Hastings and Beck, 2004).

#### *6.B.2.3 Intimate/sexual*

The women spoke fondly about how they made close friendships with peers and, at times, formed intimate relationships whilst in SS. When the women spoke about their close personal relationships there was evidence of diversity in that they were in same-sex relationships whilst living in the community and with other patients, whilst also having a boyfriend, being bi-sexual or being married and having a husband.

*“...I used to go over (social hub) because my ex lass used to go but it was a bit awkward because my ex lass got put on the same ward the one I have just finished with this year but they were all right about it I used to go over and my ex lass from (\*other ward) was put on the same side as my ex lass...”* (Steph).

There was an indication of immaturity in close relationships:

*“...In the hospital...such and such is my boyfriend, and we are getting engaged next week”* (Nurse Amy).

The women talked about relationships in terms of an all-or-nothing status, conceivably because of the women surviving previous abusive relationships.

Whilst living in the community, participants reported times they spent with other gay women.

*“I was hanging around... with gay people because I am gay myself, they were horrible...”* (Margaret).

Here the participant was befriended by other women who abused her, and this is potentially an indication of unhealthy relationships, although Margaret may have difficulty forming and sustaining healthy relationships in any event, which is exacerbated by her bi-sexual identity. Another participant told of her sexual identity:

*“...that’s my boyfriend its going good I was with him years ago as well then we got back together on Wednesday I love him but when I was in (\*hospital) I did have a girlfriend so I like a bit of both but he doesn’t know that and I am not going to tell him there was a chance that me and her would get back together but she lives right back in Cumbria, it’s the miles, it’s too far”* (Steph).

The women had engaged in the sex education classes offered within the service. Healy *et al.* (2011) found that adults with ID needed sex education to enable sexual expression and autonomy.

*“There was meetings, yes there was CPAs and tribunals that’s it really and sex education I did that as well”.* (Theresa)

#### 6.B.2.4 The nurses

The women spoke affectionately about the nurses and were confident that they were passionate about their job.

*"I liked \*...there on the ward... she helped me a lot, she kept me right..."*  
(Theresa).

However, the women expressed dissatisfaction about the way the nurses on the ward changed every six months, remarking that this generally unsettled them and made them more anxious. The women were objectionable to decisions made by the ward managers in relation to the limits placed upon the nurses, which said that the nurses had to remain in the ward.

*"I feel like a lot of nurses just stay in the office and I feel that they should come out and I feel that they should be interacting with the patients and should go to more core sessions...I know it's not always possible because they have a lot of work and stuff, but I feel they should be able to come on leave with us and they never get to do that ever even external leave I mean they don't get to do that. Apparently, the ward manager had said that the nurses cannot do that ever and that is not right because at the end of the day they should all be involved. There is only one time of year that they can do it and that is on the away day and that is shit really it isn't fair for us and it's not fair for them, so just little things like that. The problem is if you did communicate with all of them better, I know what they are saying and they change the nurses every 6 months to a year which isn't good either, it is and it isn't. It has got the pros and the cons. They keep changing the nurses it unsettles us and makes us more anxious because it is not just about that, it's about the report and the presentation of the report..."* (Olivia).

This meant the nurses could not leave the ward to go on outings and activities, and the women stated they would prefer to see more of the nurses, especially on high days and not just for routine interventions. This was a hindrance in the patient/nurse relationship.

Ruby discussed in detail how she appreciated the support from her nurses.

*“...I have a fantastic nurse called [\*] ... she is sitting there nice and peaceful... she does my meds, she does my depot, she does it really really, well I like her I really really like [\*] a lot...” (Ruby).*

*“...\* is perfect, like her sense of humour, she has a good sense of humour, a lovely smile, she helps me and she talks to me, makes me feel jolly, look at her sweet cheeks, yes [\*] is fantastic she is fantastic she is lovely I like [\*]” (Ruby).*

Similarly, Lauren told of the range of support given to her by the nurses.

*“The staff...they talk to me if I am upset and stuff like that and they are there to take me places and stuff like that...” (Lauren).*

One of the women talked about how she had formed relationships with other women, yet the constant in her life was the support from her nurse.

*“...the best support is my named nurse [\*] I get on alright with one of the patients \* and I used to get on with some other girls but that was on the ward, but they have left now they have gone into the community...” (Penny).*

Pamela described how she talked more to the staff,

*“...actually, I speak to staff more than patients... ... I have my named nurse its [\*] also I have a care team who are [\* and \*] Keyworkers they just help me and check I am stable with checking my mental health is stable how am I doing am I feeling not okay do I need extra staff do I need two staff...” (Pamela).*

The women agreed that the nurses were the supportive factor in their lives.

*“Probably my named nurse [\*] my three care workers and my girlfriend I was with at the time, so I had [\*male HCA] and [\*female HCA] and [\*] little... ahhh...they were lovely...” (Steph). “one of the nurses I really particularly get along with, I think it is because she is in the same age group you have studied*

*her today apparently, she is on shift today, and I go to her quite a lot when I am emotionally quite low or sometime, I will go to her, but I think it is because we are the same age...” (Olivia).*

The proposition that Olivia goes to her named nurse because they are the same age is interesting, and not aligned to current thinking which states that age is not a preferential issue when compared to gender (Chur-Hansen, 2002). However, older nurses are crucial to the workforce and vehemently defend their standpoint as a bedside nurse (Parsons *et al.*, 2018).

The nurses said they were committed to support the women to create and maintain family relationships, and often this was intricate and involved legalities. Nevertheless, it did involve talking about families, although the nurses felt uncomfortable talking about their own family and were often unsure of the right approach. They were uncertain what to say since the nurses were acutely aware of the fact that the women can be jealous of ‘outside’ lives. Some of the women and nurses accepted that talking about families was acceptable, whilst for others this could not be tolerated. This research suggests a process of relationship acceptance since this is reality.

### 6.B.3 Gender

The women and the nurses were loquacious on the issue of gender, telling the researcher their opinions and experiences of male and female staff working in the female secure service. The presence of this theme in the data was interesting because there were no questions in the interview schedule relating to gender. The sub-themes within this overarching theme were gender of staff, gender bias in service provision and a mix of male/female staff. The women referred to gender in their responses to questions 2, 3, 4 and 5, whereas the nurses mentioned gender in question 3 (interview schedules for the women and nurses are provided in Appendix 1 and 2 and reiterated at the beginning of this chapter).



### 6.B.3.1 Gender of staff

The women referred to male staff by naming specific individuals and singling them out in a way that clearly demonstrated strong feelings and emotions. The women had preferences and favourites in male and female staff, although they were explicit in expressing their views about male staff in a love/hate style.

*“... I fucking hated him, I fucking hated him, I fucking hated him he was called \* I fucking hated him” (Theresa).*

Here the participant spoke vehemently of her hatred of a male nurse. Conversely, when Theresa continued in the same sentence, she went on to say, *“...I hated \* the other manager as well...”* (Theresa). On the one hand, the level of hatred could be directed towards the role as manager the male nurse was in, while on the other it could be an indicator of a negative feelings towards male nurses, or a particular male nurse. Theresa may have an issue with men with an authoritative role in her life, which is unsurprising given her previous experiences. The women talking of hatred of a person in charge is not unlikely in SS since the issue is one of power and control. However, it must have been problematic for the nurse/manager to sustain a therapeutic relationship in these complex circumstances. Nevertheless, the presence of male staff in the women's experiences had made a significant impression.

The women said they would need courage to ask a male member of staff for help.

*“there are sometimes men on here and have been in the past I am not bothered by it at all ...well I have never asked anyone for a conversation by a male...I would have to pluck up the courage and ask but I never have ...I find it easier to talk to the female staff here” (Pamela).*

This participant was showing that her preference has been to seek support from female staff, although there are few male staff available in which to seek support from. It seems that the opportunity was limited for the women to seek support from male staff in any event. Therefore, the provision and availability of male staff is the systemic problem, and unfortunately the women cannot be guaranteed there will be no men in their lives again.

The sense of love/hate was expressed further:

*“...I loved [\*male nurse] and not [\*male nurse], I hated him I used to get upset”*  
(Ruby).

Here the participant was referring to male staff with a deeper narrative placed on the negative feelings. Whereas another participant had positive comments about male staff, stating *“...I got on great with him...”* (Theresa). When living in the community prior to admission Pamela commented on the support team she had, stating *“I was living with an all-male care team...”* (Pamela). This demonstrated the level of detail in the narrative from the women about male staff in their experiences.

Currently within the women’s secure ID service the provision of male staff was a temporary arrangement, managed and deployed to the SS unit from the nurse bank or sessional working from the MDT. However, the transient nature of staffing into the ward was unsettling and unproductive for the women. The nurses said that when there was male staff placed into the ward from the nurse bank this was short lived as male staff were needed elsewhere in the hospital for male wards and thus taken from the women’s service.

*“...males are often needed on other wards for male observations...in the past we have had a few males and they have been taken off us and moved elsewhere anyway...”* (Nurse Charlotte).

The nurse here was accepting of a situation and was somewhat defeatist on the point that male staff were employed into the female secure service, only to be later redeployed. But she maintained her position by stating *“I would like a few more males”* (Nurse Charlotte).

The nurses saw the presence of male staff as a positive influence on the women in the secure ID service. They saw this positive effect:

*“...because of trauma history and because of what the women have experienced ...male role models are important”* (Nurse Charlotte).

The notion of role modelling was talked about in depth by another nurse:

*“...they respond really well to [male staff] ...they are good role models” (Nurse Bella).*

Here, Nurse Bella acknowledged the positive influence and captured the benefit to the women:

*“...which is why I want a few more so prove that not everyone, I am not saying that it has always been a man who has caused them trauma, but I feel like they should have a good male role model...” (Nurse Bella).*

The nurse was simultaneously acknowledging the trauma the women have experienced and how the presence of male staff can show the women, that men in their life can be positive.

However, one of the women reported on her interaction with men outside the secure service:

*“...we have a lot of female and I think we only have one male staff and then the odd bank, so the male banks pick up... I used to go to my dad...he’s not really my dad but I call him Dad, he’s been with mam since I was six” (Olivia).*

The irony here is that the women may be seeking assistance from their abuser because of the absence of male role models within the service.

#### *6.B.3.2. Gender bias in service provision*

The nurses eloquently described their utopian visions for the women’s secure service, articulating the difficulties they faced by comparing it to provision in male secure ID services.

*“...my theory was we will have an assessment pre-treatment and then a treatment pre-rehab...there is no community provision either for our women...the male equivalent is a step down in the community... and a rehab house where the patients go from the ward...” (Nurse Bella).*

Nurse Bella furthered the point:

*“we need to replicate the male service...to prepare the women for discharge... women are always at a disadvantage for what we have to offer and always has been, I think there has always been a better scope for men...their treatment pathway looks a lot better”* (Nurse Bella).

The nurse was verbose in her outrage at the lack of service provision for women with an ID in SS following service reconfiguration from a women's only service that was created a number of years ago (DoH, 2002).

Another one of the nurses told how they had to compete for access to services for the women.

*“...day service activities...far less available for the ladies as there was for the men, I found that we struggled a little bit, we had three ladies in particular who were very keen on woodwork, we really had to fight to get them a session in the woodwork department”* (Nurse Grace).

This involved having to battle against a service that was predominantly male led for male patients. This demonstrates the level of campaigning and championing the nurses had to do as part of their job in, against the dominant discourse, in order to seek services for the women.

#### *6.B.3.3 Mix of female and male staff*

The mixture of having male and female staff was referred to by the women and the nurses. The perspective of the nurses was that having male staff in the team was positive for team dynamics, in that *“...it works with the staff team...”* (Nurse Bella). The point was furthered by this nurse when she discussed the behaviour of the women towards each other:

*“...I think we need some males to make it less bitchy...I do think males do split that up a little bit...I do feel like we need a few more males”* (Nurse Bella).

This was supported by the women:

*“...we had males, we had [\*] but he has gone to the community and is working with people out in the community, so we did have a male member of staff on the ward... I get on with both and it is no different, no” (Lauren).*

Male nurses are largely underrepresented in the profession, as there is currently only 11% of RNs who are male (RCN, 2020). They are also more likely to be promoted to nurse directors (Santry *et al.*, 2010), resulting in less male nurses on the ‘shop floor’.

The women described moving from mixed staff/patients to all female as ‘weird’, and how this caused their confusion in the gender of staff. This was in relation to the mixed staffing in the children’s ward then having predominantly female staff in adult services, which contradicts the literature in support of a gender-specific service (Sahota *et al.*, 2011). The women compared the mixed gender of the staff team in children’s service to the predominantly female staff in adult SS. The women were keen to know why there were mixed staff in the male services. The nurses were proponents of male staff working into the female secure service by acknowledging how male role models could be positive for the women. This became difficult, however, when the women accused male staff, possibly stemming from the learned behaviour of how their relationship with men had been for their entire lives. As such, they may be unsure of how to communicate with a man and resort to what they knew to be true. This was compounded by the current agenda on disclosing and challenging abuse from the #metoo campaign. Indeed, women with ID ought not to be excluded from this. Yet, unfortunately, this issue undoubtedly would deter male staff from working in female SS. However, the nurses agreed that the presence of male staff had an overall positive affect on the women in their daily living in the ward. This supports the research by Krumm *et al.*, (2006) which found that staff did not view single sex wards as a protection for vulnerable patients. Furthermore, Mezey *et al.*, (2006) found that separating female and male patients would strengthen the stereotyped roles of male patients as dangerous predators and would not enhance the women’s safety.

*“There was male and female staff... both, it wouldn’t bother me, one of the staff, males, always goes red, I made him go red..., because I started my periods, I was eighteen and I said what do you have to do, if it was a male, I would ask them, I’m not bothered I would go to male or female staff”*  
(Theresa).

In her narrative, Theresa told the researcher she could engage with male or female staff, yet this was linked with how she purposely disclosed personal issues to cause male staff embarrassment. This is consistent with the literature, which states that women with an ID at times publicly disclose inappropriate aspects of menstruation (Rodgers *et al.*, 2006).

Participants agree that a mix of staff is important:

*“...no difference, for each bedroom there had to be two staff...the male staff was dead canny... there was other male staff, but it was all female patients on the ward there was no mixed patients...”* (Steph).

*“I think a mix of staff because I do think the positive male role model is an essential part, absolutely totally and utterly”* (Nurse Amy).

However, the nurses accepted their own gender and that of the women in a sense of helping them to understand the women and to assist them to do their job:

*“I can relate better to the women because I am one...”* (Nurse Hannah).

The women compared their experience of male/female staff in children’s secure service to that of the adult secure service.

*“...there was male and female staff...in the children’s ward...”* (Margaret).

*“It was mixed staff in children’s...”* (Olivia).

This is evidence that the presence of male and female staff was accepted practice in children’s SS. Whilst the adult SS moved to single sex accommodation, the national

secure adolescent service continues to offer mixed sex accommodation, and Olivia was referring to her experience of this. As such, research has reported that mixing gender in adolescent services was a crucial aspect of treatment in a developmentally appropriate environment (Crutchley and O'Brien, 2012).

The presence of male/female staff provided choice and diversity for the women.

*"I actually preferred that [mixed] because you had a variety of people to talk to and not just all women..."* (Olivia).

Here Olivia was showing how she understood the difference and, as a result, engaged differently. Olivia furthered her position:

*"...I didn't really go to the females I went to all the males and I wouldn't really speak to the females because I didn't trust them... or wouldn't know how to talk to them... so I associated that with that"* (Olivia).

This is a profound stance, although Olivia did not say whether this was explored whilst she was in the children's service.

The presence of male/female staff at school was also referred to by the women.

*"...in the school... it used to be all the males ...talking to me...to help me, it was never the females..."* (Olivia).

The presence of male staff was clear at school. This shows that the women had experienced male/female professionals as a child, adolescent, and young adult. This stance was carried forward into the female secure ID service.

*"...when I came here it was all females and I was like I don't like it basically"* (Olivia).

This participant was questioning why there is only female staff in the adult service and grappling with the transition.

*"some people find it easier to talk to males than what they do females and people find it the other way round so there should be a lot more variety..."* (Olivia).

Olivia was a keen proponent for a diverse staff team:

*“there can be male staff, but not with personal things...like him and [\*] were alright with me and my lass”. (Steph)*

The participant was telling the researcher how accepting and understanding the male staff member was of her same sex relationship, although it was abundantly clear that only female staff could assist the women in areas of personal care.

It seems the move to implement single sex secure units has created gender division by separating male and female patients, and the result has separated male and female staff. It has been suggested that the policy needs to be reconsidered (Felton and Abu-Kmeil, 2012). There is noticeably a lack of male staff in the service, and the women wondered why that is.

*“There are not much in the way of male staff... Probably because it is a women’s ward, I don’t know” (Olivia).*

The women questioned the staffing on the ward and compared it to the staffing within the male SS. They wondered why there were mixed staff in the services of their male counterparts, yet very few male staff in their own service (predominantly female).

*“I think in the men’s ward there is loads of women – staff, you know what I mean so I don’t know why there are not many men here” (Penny).*

The limited availability of male staff, and the predominance of female staff, was expressed by the women with a sense of injustice. Moreover, female staff working in male SS experience fear of violence, while male staff working in female services experience a significant higher level of fear of false accusation from the women (Hawley *et al.*, 2013).

## PART C: The Future

### 6.C.1 Long term planning – the end game



Discharge was a theme in these data that was a unified goal from the women and the nurses. The sub-themes within the overarching theme were discharge, community living, best place, advice to nurses and advice to students. The women were keen to demonstrate how they were working towards the prospect of leaving the secure service and having a home of their own. Equally, these nurses were just as keen to show how they support the women to achieve this.

#### 6.C.1.1 Discharge

To prepare for discharge the women were engaging with the multi-disciplinary team (MDT), specifically psychology, psychiatry, occupational therapy, and nursing staff, to demonstrate that treatment had been successful, and they were ready for discharge and community living.

*“It is like helping me to move on and how I can be a different person when I get out and how I can manage better when I am out and how I am going to deal with things when I am out” (Penny).*

The motivation for the women was an ambition to live in their own home within the community, and their narratives were aspirational. There was an agreement between the women and the nurses that discharge was their goal and end game, realising the best conclusion is that the women would not be living in the secure service forever. However, it was also accepted that the women have more mental health needs which will continue in their discharge, and although they may have less criminal behaviour, they are overall more likely to be readmitted following incidents not leading to conviction but requiring admission to higher SS (Sahota *et al.*, 2010). This suggests that the future is bleak due to the disproportionate outcomes for the women.

Conditions to discharge the women were dependent upon involvement with treatment, and leave was discretionary, as the women were at the mercy of the law courts.

*“to shorten the time sentence, you can ask for a tribunal within the first six months after that then its yearly after that then they said you need to do the DBT because I did it and I flew through it...with my dyslexia” (Steph).*

To plan for discharge there was a requirement to engage with treatment, which included, DBT, RODBT or TIC, as discussed earlier in this chapter. This is because the aim of secure inpatient services is to enhance the mental health of mentally disordered offenders whilst reducing the risk of recidivism (Duke *et al.*, 2018).

Steph conveyed her additional problems in terms of having a learning difficulty in the form of dyslexia, although it seemed this was addressed in terms of the support she was given; see section 4.4.2 for a discussion about participants in this study with a specific learning difficulty, including dyslexia. The nurses accepted the difficulties but maintained their commitment to help the women achieve their goal of discharge.

*“the ladies I’ve got now, we hope to discharge back into the community because it wouldn’t be beneficial to remain in service longer than they need to...with Transforming care the aim is to get everybody out, all the ladies have an estimated discharge date, so we try and stick to but that is very dependent upon treatment engagement” (Nurse Amy).*

Here the nurse showed how she was supportive of discharge whilst balancing the need to engage with treatment. This sub theme in the data is an example of how the participants made sense of a complex situation and the prospect of discharge was a joint enterprise between the women and the nurses to enact change via discharge.

The additional challenges the women face were expressed in relation to how they would get to a discussion about discharge, in terms of remaining substance free and showing the ability to make friends with the right kind of people.

*“I am still waiting for some leave as well from outside the grounds because the Dr’s and the courts decide and that, so I have to stick to it first ... they are working towards getting me back out there again. Keep off the drink and the*

*drugs and make friends with the right people and not run away or set fire to things or drink again..." (Olivia).*

Olivia was talking of how she is aware that she has made mistakes in the past, whilst taking comfort in the support available to her.

*"...I will have staff to support me outside the community, but I am not going yet... because they haven't found me anywhere, yet it just takes time" (Olivia).*

Here Olivia understood the constraints on service provision, and she was working toward discharge but appreciated the right placement is difficult to find.

*"...I have been here a long time and sometimes I am like when is it going to be my turn and I sometimes get jealous, that can be hard..." (Penny).*

Here Penny talked about how difficult it can be in the secure service, particularly seeing others move on, and how time is needed to come to terms with their own situation. This was substantiated by the nurses:

*"...a lot of our ladies are diagnosed with personality disorders, and a part of that is known jealousy, jealous of other ladies, it is quite noted, and often presents as risk behaviours" (Nurse Charlotte).*

The problem here is to reconcile the constraints between discharging the women and the impact on the others who are not ready for discharge yet. Giving the right support to an older person in SS has been identified as a concern, as older persons experienced more integration when they were in a setting with those of a similar age as opposed to services dominated by younger adults (Visser *et al.*, 2019).

The nurses were making inroads with implementing Transforming Care, despite the complex nature of the women's status.

*"we've got ladies who are 37/41s so that's not always as easy... a lot of our ladies would require more of a single person, a sort of bespoke package which isn't always available, so that ends up in us being a stuck a little bit, we've got a lady she's been in service for fifteen years ...but times ticking on for her now really, but we just get stuck" (Nurse Amy).*

It has been found that the age of those in SS is increasing and an age-specific service may need to be considered (Parrott *et al.*, 2019). The success of such transition largely depends on planning, support and consistent support maintained following discharge. The government agenda Building the Right Support (NHS England 2015) aims to address the scarce provision of community services. However, authors have criticised the implementation of Transforming Care (Bubb, 2014) as a means to which patients will be admitted to private sector hospital beds (Taylor *et al.*, 2017). A shortage of appropriate community hostels can be attributed to a longer stays in SS (Brown and Fahy, 2007).

#### 6.C.1.2 Community living

The women who had previously experienced SS but were now living in the community told the researcher that living in their own home was best for them, albeit with support. Conversely, there were difficulties in sustaining community living. At times some of the women who had previously been living in the community were readmitted to SS when the situation broke down:

*“...I was out in the community once, it was for three months, and one of them made an appointment for me to see a doctor, and the doctor thought I was displaying rather wayward behaviour ...”* (Pamela).

Pamela was speaking about her last community placement which unfortunately had broken down, and she had now been in the secure service for ten years. This is congruent with the literature, which shows that those with ID were found to be more likely to have long stay admissions in a medium secure unit, with an increased likelihood if they were admitted from prison (Hare *et al.*, 2018). Pamela was admitted to the secure service from prison, which means the likelihood of her living independently in the community is slight. Her potential outcomes were discussed by one of the nurses:

*“we are desperately desperately trying to get her out and we just can’t, you get stuck because of money, and it’s quite frustrating for the team because we know that she shouldn’t be there anymore she’s sixty odd, she’s lovely, and*

*we would love her to stay but you want her to go out into the community and experience a bit of a life in the community while she's still here (Nurse Amy).*

Research indicates that the average length of stay in a medium secure service is increasing (Shah *et al.*, 2011). It would appear that both practice and policy need to be responsive in this area.

Meanwhile, the women who are now living in the community are living their best life, have jobs, have a social life and are attending further education.

*"I've been to work today in (local charity shop), I love it, I work there on a Monday because I am busy every other day and I am busy, and I will be knackered tomorrow, I am in a band and we are playing at (\*local pub)" (Steph).*

However, it is crucial that the right placement is sourced, which is problematic. Following the Winterbourne View scandal, the subsequent implementation of the Transforming Care agenda (Bubb, 2014) has produced numerous criticisms. It seems that there are success stories to be told and ought to be heard.

#### *6.C.1.3 Best place*

Overwhelmingly the women said their ideal living situation would be in the community with staff support available twenty-four seven, just like they have in the ward except living alone.

*"...my best place would be in the community... No, it would be living on my own with staff support now and again but it would have to be staff there for twenty-four hours...so, like there all the time ..." (Lauren).*

This participant was describing how she could live in her own home in the community with support, just like in the ward but in a geographically different location. Accepting the fact that they need the support, the women were aspiring to live their best life with the support of the nurses to achieve this. This was a strong motivation for them engaging with treatment, abiding by the rules and regulations

imposed upon them, and hoping for a chance for a home of their own and to live independently.

Discharge was a consistent focus for these nurses.

*“...we hope to discharge back into the community...it wouldn’t be beneficial ...to remain in service longer than they need to...”* (Nurse Amy)

Inappropriate lengthy admissions are echoed in the literature (Duke *et al.*, 2018).

*“...our ward also needs to replicate [\*male service] ...to prepare the women enough for them to be able to be discharged...”* (Nurse Bella).

*“...our outlook is to get them out, to provide the treatment then to aim for discharge...”* (Nurse Charlotte).

*“...we had three discharged to home so that shows maybe how the service wasn’t required for them...”* (Nurse Emma).

However, the experience of discharge differed in the women.

*“I was thinking I am not going to be discharged...but then they changed my diagnosis...”* (Olivia).

*“...I got a discharge from there and I went to go and live in (Yorkshire area) and it just went wrong there...”* (Margaret).

The women and the nurses were working simultaneously to prepare the women to live in the community, and the problems they faced seemed to be sourcing the right support package and employment opportunities for the women. It is now known that it is harder for women to succeed in any workplace, let alone for those with an ID. It is tougher for women to achieve, to get opportunities, to get training and to succeed in the workplace, which is a recognised problem in contemporary society (Heilman, 2012). The women in this research who were currently living in the community were living a happy fulfilled life.

The women took the opportunity to give the staff advice, by saying they wanted to be treated nicely, not awfully.

*“my nurse [\*] on the ward, she respected me, I had never seen a squirty gun in my life, [\*] she got me one... I was only twenty-one so someone put a cake in me face, it stunk, they knew I can take a joke” (Theresa).*

Humour was noted to be an important aspect to daily life in the secure service, and this was equally found in research conducted in a medium secure service with men who have ID (Inglis, 2009).

*“I like a practical joke, [\*] did it for me, because she knew I can take a joke, some girls in there don’t take a joke in there, they get paranoid...” (Theresa).*

However, the women added a word of caution here, to alert nurses that humour has its place in the right context and when the mental health of the women allows. The women are asking for respect from the nurses and outlining episodes in their experience when they were shown respect. Theresa was reporting from her experience about a memorable time in the secure service when she was valued. Theresa was also saying here that the humour was an illustration of the level of understanding, trust, and person centredness present in the relationship she had with the nurses.

The women also advised the nurses to speak in an even tone and not to shout. They also asked for respect from nurses and said that little things meant a lot.

*“She needs to talk to the staff...the lady needs to talk to the staff, and they need to listen to her” (Ruby).*

The women were explaining in a subtle way the art of mindful listening, and they were asking the nurse to zone out distractions, concentrate on the moment and give them what they need at that particular time (Ali, 2018).

The women were notably friendly and helpful to students who were on placement in their ward or home.

*“Tell them about what to expect and what to do you know how to help patients on the ward if they need help tell them that if they may need to chat if they feel bad, they might need to go into a private place because a problem shared is a problem halved find out how they tick get to know about them ...tell them to listen...what to expect...see how they tick, get to know them”* (Pamela).

Giving advice to students in this way demonstrated a nurturing side to the women in terms of understanding the limited knowledge a student would have when placed into the service. The notion of empathy is displayed here whilst giving direction to learners in terms of what the women wanted from students. The women were aware of the researcher's role in supporting students, which could have initiated this response.

The women gave advice to students around diction, tone of voice and words to use.

*“Just be calm keep your voice low, try and help the situation give them time out and ask if they want time out ask if they want prn...”* (Steph).

They outlined the complexities involved in managing difficult situations and gave further advice in terms of how incidents may unfold.

*“...if they want reassurance then try and help the situation don't go off on a high then if the prn doesn't work pull their alarms... only pull alarms if they are kicking off...”* (Steph).

The advice was communicated by the participant in a way that mirrors how managing behaviour and incidents may unfold in a chronological order.

*“... then more staff to restrain a patient, it can be up to six staff, maybe more”* (Steph).

The women seemed to be anticipating any potential anxiety the students may have and were noticeably deescalating those anxieties when describing how episodes may become an issue of restraint. Undoubtedly this advice would have a more favourable outcome for the women, while at the same time warning students of what



can happen in the secure service. It seemed the women were aware of the necessary skills needed to manage incidents, which was highlighted in a recent government report stating that staff lack the necessary training and skills required for managing restraint or seclusion (CQC, 2020). Preparing students to manage complex situations is attempted in HEIs using simulation, however when the women are giving the advice this is more powerful than any lecturer with a mannequin could replicate.

## 6.2 Findings from the methodology - objective 1

The methodology in this research study was a narrative approach through semi-structured interviews and is discussed in Chapter 3: Methodology. Chapter 3 also provided the objectives in the study and were reiterated at the beginning of this chapter. The first objective was to develop innovative methodological approaches in exploratory research with women who have an ID and are in SS, and this section explains how the findings met that objective.

A review of the literature found that research conducted using a narrative approach with women who have an ID (the women) is limited and scarce (Coid *et al.*, 2000; Lindsay, 2004; Crossland, 2017), let alone research simultaneously interviewing nurses who support them (the nurses) (Mason, 2010; Dalgarno and Riordan, 2014). These populations are complex because of what has happened to them in their journey and what makes them who they are, their identity, where they will end up and what is their end game. These issues are synonymous as well as self-evident and conducting research with hard-to-reach vulnerable groups can deter researchers from conducting such studies. This perpetuates the limited corpus of evidence available to address the needs of this vulnerable group, which is a circular argument and illustrates a disparity in the literature, though the findings from this research study can go some way to contributing to filling the void. This section illustrates the unique approach adopted in this research study by illustrating how the presence of a third party was acknowledged, anticipated, managed, and empowered the women, as well as adding richness to the data. The inclusive style in conducting the

interviews in this way is a unique feature of this research study and shows the innovative methodological position.

The research was designed to include the presence of another person during the interviews as well as the women, which was an important aspect procedurally as well as in data collection. The presence of a third party was considered in terms of assessing the rigour in the research, specifically reliability and validity (see section 4.7). The researcher was mindful to carefully consider the needs of all participants at every stage in the research study. Alongside this, including and managing the presence of staff member(s) during the interviews helped to maintain the rigour in the study. Additionally, a researcher adopting this methodology needs to consider how the presence of a third party with participants who have an ID can influence a study (Caldwell, 2013). This research study included the third party to ensure the women were able to tell their story how they wanted to. The table below illustrates the presence of staff during each interview and their job role.

**Table 14: Staff present during interviews with the women**

	Location of semi-structured interview	Registered nurse present	First health care assistant present	Second health care assistant present	Home leader
Lauren	The ward- Site A	✓	✓	✓	
Margaret	The ward- Site A		✓		
Olivia	The ward- Site A		✓		
Penny	The ward- Site A		✓	✓	
Pamela	The ward- Site A		✓		
Ruby	Step down service-	✓	✓	✓	

	Site B				
Steph	Own home	✓			
Theresa	Own home				✓

The presence of another person with the women in the semi-structured interviews was expected because the researcher was aware of this custom and practice in SS (NG10, 2015). Particularly, that there would be legal restrictions and/or observations placed upon the women, meaning that in some instances the presence of another person was unavoidable (MHA, 1983 Code of Practice). Staff who observe patients in secure settings are required to attend mandatory observation competency assessment training with updates (RCP, 2010). However, the practice of observation is moving toward therapeutic observation and positive engagement (southernhealth.nhs 2020).

Semi-structured interviews hear the subjective experiences of a participant but may require a degree of facilitation by the researcher, hence the decision to include interview schedules in this research study. However, participants with an ID pose an additional challenge in that techniques to maximise the responses, such as silence, repeating and summarising responses, can give richness to the data (Sigstad and Garrels, 2018). It was important for the researcher to include the third party from the beginning giving, all those present an explanation on confidentiality, the interview protocol and what would happen afterwards. It was possible that the staff present were likely to have a history of working in institutions and may have been institutionalised themselves (Bigby *et al.*, 2009), which meant the presence of a third person could have been detrimental to the findings.

Had this design of this research study not accommodated staff to be present during the interviews, those women who required staff to be present could not have been included in the research, meaning they could not be a participant or interviewed. This methodological approach enabled the women to be participants and subsequently facilitated their voice to be heard.

There were planned strategies to minimise distress during the interview for participants (appendix 12 provides the ways the researcher would do this). However, having staff present with the women was an additional protection since the staff could observe for any possible signs or triggers which they could alert the researcher to. Ethically, the women had no personal benefit from participating in the research, and even though attempts were made to maintain neutrality a therapeutic element presented itself when Olivia said:

*“...I have dyslexia... if I put a coloured sheet over it I can read it quite well... but then if it is on coloured paper I sometimes don’t...if there is a yellow sheet and I put my acetate over it, it counteracts it. I keep saying to the staff I must be thick I can’t do this...I don’t have a learning disability...I must just be thick. I keep saying, that don’t I?”*

Olivia was describing an intricate process of managing dyslexia and how she could utilise materials to support her dyslexia. There are complexities involved in managing a learning difficulty, something that the non-ID population struggle with (McBride 2019), so therefore it is unsurprising that Olivia was experiencing difficulties yet playing the whole thing down. At this point the HCA contributed by saying; *“It’s not true though, is it?”* After a pause from them both, the HCA continued:

*“You are doing Maths and English and you stayed back today and did more Maths than what you were expected to do, and you do really well you just doubt yourself”*

Olivia concurred with the point made by the HCA; *“Yes I doubt myself.”* The input from the HCA and exchange in dialogue with Olivia demonstrated how the staff present added value to the data. The HCA continues; *“it’s just confidence”* Olivia closes the conversation; *“yes its confidence, I think because when I was at school, they just used to do it for me.”* Paradoxically, by adding factual information to the data Olivia was empowered in the process.

There was a possibility that participants would disclose an issue that may need to be reported and having staff present was an added protection should this situation

occur. When one participant talked of the abuse she had suffered by her peers, she stated,

*“I was assaulted not by staff but by a peer and I don’t want to mention her name at all... every day it was horrible that ...I can’t forgive her...I can’t forget it it’s still there I talk to them about it... they got a shock; they were shocked when I told them”* (Pamela).

The HCA nodded to Pamela then to the researcher and said, *“yes we knew, it’s awful its good they are helping you with it.”* Here the HCA was acknowledging the woman’s account of a distressing time and informing the researcher the issue had been acknowledged and was being dealt with.

The staff present may not have known the full history or had the opportunity to hear personal accounts of the experiences of the women. Whilst information is available to nursing staff, in electronic notes, these are written by professionals. Notes available for nursing staff may be in the form of a summary care record, which includes current medication, known allergies and demographic information (NHSdigital, 2020). People with an ID tend to access many different services and many different organisations. To address this there is an attempt to streamline the access and sharing of information in mental health Trusts and between health and social services (NHSdigital, 2008).

Documentation was cited by one of the participants:

*“...in your training...I don’t think you get any experience of the electronic note systems...or documentation, again I don’t think you get a lot of opportunities”* (Nurse Bella).

This methodology enabled the staff present to hear the story from the women directly, as opposed to a professional writing a report. This was evidenced after the interview had ended with one of the women and as we all stood up to leave the room, the RN present said, *“it was good to hear Ruby saying those things in there”*. This quote demonstrates that the RN present was not well informed, did not know

the detail and certainly was not aware of how the women viewed their own experiences. It could be argued that the nursing staff supporting the women should know everything about the women as part of clinical practice. Yet there is a balancing out of care roles within the secure setting, and perhaps the stories, histories, hopes, and dreams are left to be told to another person as opposed to those supporting them on a daily basis in the secure service. Whatever is the reason, this methodology enabled the women to tell the story and allowed the staff to be present and hear it. It is important for those who are supporting the women to have a full understanding of the women's experience from their own lens, particularly as the model of nursing is moving to trauma informed care.

The women acknowledged the presence of staff and included them in their responses, particularly when asked question 5, where do you get the most support?

*"for help...I would go to them (points to the Home Leader) ...I would go to them, I would talk to some of them..." (Theresa).*

Here Theresa was contextualising her response by including the staff present, acknowledging the question and showing how she can relate her response to her contemporary world. Furthermore, on question 5 Olivia said, *"... I do get help from her ...at the other service as well."* The HCA added clarity, *"She is nothing to do with the trust, it's the advocacy service"*. The HCA was acknowledging the additional support Olivia was receiving outside the NHS from an independent person. Olivia and the HCA agree on the point, with Olivia stating *"...yes she is based here, she is based in this hospital here"*. This shows how this approach to conducting the interviews in this way can consolidate the views of the women and the staff who were present.

Similarly, one participant answered question 2, *What are your experience of secure services?* with *"... I haven't... just this ward and next door"* (Margaret). The HCA contributed, *"You were on a medium secure and now you have gone on to low secure"*. This addition by the HCA was important because it told the researcher that

Margaret had progressed in her treatment and was upgraded to a less restrictive service. Had the HCA not been present, the researcher would not have known this.

On a return to the secure service, Olivia approached the researcher, smiling and welcoming her:

*“hello nice to see you again...I want to tell you about three other people who help me, it's my named nurse and the HCAs.”* (Olivia).

This shows how this participant thought about the interview questions, recognised the researcher and then took the opportunity to tell the researcher more. Olivia could clearly differentiate between regular and research conversations.

On the return to Steph's house to check the interview transcription, she reflected on the section where Steph talked about her current boyfriend:

*“I love him but when I was in [\* hospital], I did have a girlfriend so I like a bit of both but he doesn't know that and I am not going to tell him there was a chance that me and her would get back together but she lives right back in Cumbria it's the miles it's too far”* (Steph).

Steph interjected at this point:

*“but now he does know, and he is ok with it, he's alright he hasn't got a choice”* (Steph)

This shows that Steph had something to add, that she had been proactive after the semi-structured interview, and importantly that she wanted to tell the researcher. This is evidence of empowering the participant through participation in the research.

This study cannot be labelled as using individual interview, dyadic, triadic, joint or focus groups. Neither can this study be described as having a proxy, supporter, or family member present. Dyadic interviewing originates from family research and acknowledges the symbiotic relationship between the participant and a significant other, for example couples (Morgan, 2016). This approach is where two participants,

the participant along with a spouse/care giver who has a significant presence in their lives, both respond to open-ended questions, (Morgan *et al.*, 2013). Dyadic interviewing is not fully applicable to this research study since the interviews took place either on a one-to-one basis, or with one, two or three others present. However dyadic interviewing is an emerging discipline and being encouraged to adopt within the field ID research (Caldwell, 2013).

Triadic interviewing is a method of interviewing where there are two significant others present as well as the participant. Those who can inform the research, give prompts and reminders when the participant is unable or reluctant to, for example children and adolescents with parents (van Staa A, 2011). This research study was seeking the views of the women about their experiences, not from a member of staff. Whilst the staff may know a great deal about the women, they may not know the nuances or complexities of the women's experiences. Indeed, only the women themselves would know their complete history, their own journey and how they wanted to tell their autobiography (Chappell, 2002; Northway, 2010).

For this research study the closest definition available is Riessman's (2008) description of a Trialogue. Although Riessman's discussion relates to the use of a language interpreter, for instance where the first language of a participant is not English. This was not necessary because English was the primary language of all the participants.

This research study is presenting a hybrid of interview styles and possibilities when participants have an ID, and through necessity are lawfully required to have another person present. By recommending a model of addressing the presence of a third party/s in the semi-structured interviews, this research proposes a model of transparency and inclusion. Particularly inclusion of the third party/s to the point that participants are assured, relaxed, and inspired, which means ultimately rich data is collected as a result. This research positions a concept that this is a blended approach to conducting semi-structured interviews and can be best described in the



acronym INTREPID. This stands for interviewing using a narrative approach with a third-party present, for conducting research ethically with participants who have intellectual disabilities.

### 6.3 Chapter summary

This chapter has introduced and discussed the findings from the analysed data, in relation to the objectives of the research study. This chapter has remained faithful to the data and has presented the findings in the chronological format of past, present, and future, telling the story the way participants did. This chapter has critiqued the findings with the current body of knowledge, showing how the findings are consistent with the literature or introduce new knowledge. The chapter concludes with a discussion of how this research study provides an innovative methodological approach to conducting research with participants who have an ID.

## Chapter 7: Conclusions, recommendations, and implications

### 7.2 Original contribution to the body of knowledge

This research study has heard from a distinct and under-researched population, women with an ID and nurses in SS. This research was designed to hear the voices of women with an ID who are vulnerable, have vulnerability factors or can be gullible to others (Nind, 2008). Hearing of their experiences in one study has enabled this research to present unique findings to the subject area in a way that has never been done before. The findings from this research add to the evidence base in three ways. Firstly, this research has brought new insights by adding to the limited evidence base and current thinking around what is already known about the experiences of women with ID of SS. Secondly, this research has shown how the nurses support women with ID in SS and reports on how the nurses view their preparation for the role as RNLD. Finally, this research has relevance for other researchers and brings new techniques in methodological styles when conducting semi-structured interviews with women who have an ID.

This research study brings relevance to the academic field because of the uniqueness of the topic, research question, aims and objectives. By proposing new understandings of the topic this study will assist women with an ID and their families, future researchers, staff working in secure women's ID service, and service provision to further the subject in a way that can enhance what is known about the lives of women with an ID. This means the research will have a broader social and cultural relevance, made significant due to the evidence that has evolved from the findings. The findings are substantial due to the extensive data generated in the research study, some of the findings concur with current thinking, yet others are at odds.

### 7.3 Limitations in the research study

This research study aimed to explore the experiences of women with an ID of SS and of the nurses who support them. There was no intention to hear from men with an ID of SS, therefore the findings can only relate to women, a group that very little is known about (Coid *et al.*, 2000; Hellenbach *et al.*, 2014) and who have previously been largely ignored.

The study was primarily concerned with how the nurses support the women and the perceptions of the nurses of their preparation for practice, therefore specific education/training models have not been explored. This means the research does not show the influence of hospital-based training schools or higher education institutions on the preparation for practice of the nurses. It is beyond the scope of this research to discuss various models of nurse education. Therefore, inferences cannot be drawn from this study to compare or favour one approach over another.

The research method to collect raw data was through semi-structured interviews conducted by the researcher to capture experiences of participants in a cultural context (Clandinin and Connelly, 2004), on one occasion. The limitation with this approach meant there was a reliance that one opportunity was sufficient for a participant to say everything they wanted to. Additionally, it was possible that a participant would have an alternative narrative in a different context, for instance a second interview, with another interviewer or in a different setting. Furthermore, would the women in the ward say something different if they were interviewed after discharge and living in their own home? This significant change in their life may alter the views they held on their experiences and, thus, their epistemological stance. A further limitation in this approach is that half of the participants had an ID and are not a homogenous group, and this means that assumptions cannot be made about styles of conducting interviews since this may constrain what a participant brings to the interview (Goodley, 1998). Having two sets of interview questions, one for the

women and another for the nurses attempted to address this issue, nevertheless it may have hindered the rhetoric in any event.

Another limitation in this research is that all recruited RNs were female. This was despite the inclusion/exclusion criteria to involve RNs working or have worked in SS of no specific gender. The limitation is found in the data where it is highlighted that there are few men working in female ID SS, which could go some way to explain the absence of male participants in this research.

## 7.4 Recommendations and future implications

As a result of meeting the objectives in this research, the findings from this study can point to the future with suggestions and guidance for women with an ID and their families, researchers, staff working in women's ID Secure Services, educators, and future service provision. The findings from this research study are timely in relation to the Transforming Care Agenda, ward closures and the continued abuse of people with an ID. The findings offer recommendations for researchers, staff working in women's ID Secure Services, educators, and future service provision. More importantly, the findings provide guidance for the women and their families. A summary of the recommendations and implications is provided below in Table 20.

### 7.4.1 Women with an ID in Secure Services and their families

1. This research study has illustrated the struggles women with an ID in SS face with often long and drawn-out complex engagement in services and legal frameworks. There is significant length of involvement for the women who are engaged with SS from a young age, and this is protracted into adult life. The journey through services for a child/woman in secure ID services may include involvement from a significant number of professionals who are in and out of their life. This includes many different services that are stretched across the country, and this transience through services should be expected, as

professionals work within service provision and endeavour to meet the needs of individuals – professionals should be candid with the women and their families. This transience has implications on relationships for women with an ID, in the sense of the limited amount of time available to make and sustain significant relationships. This research issues a cautionary note to those women and their families to be aware of this, to look for warning signs (noticeable developmental difficulties resulting in the involvement of services from a young age), and to be vigilant in seeking assistance to address worries or concerns.

2. The findings in this study show the difficulties the women experienced when transitioning from child to adult SS, and the women reflected on the transition in the sense of loss. Their loss was of their childhood and the privileges associated with being a child, replaced instead by the stricter regimes placed upon them in adult SS. This was problematic for the women and hindered progress and development. The women need to know more about the transition arrangements and associated difficulties, what is expected of them and how they can progress in adult services. The women need to have their views included and an opportunity to share their own expectations.
3. Living in secure women's ID service is not straightforward, and the women reported on the difficulties of living in the ward, communal living, daily routines, and therapy sessions they had to take part in. There is an element of lost liberty in SS, with risk management and engagement in therapies as a deciding factor in regaining liberty. One approach to addressing this issue could be a formal induction then contractual agreement between the women and the nursing staff, similar to that of a civility contract.
4. A woman with an ID may question her identity through involvement with SS, and this is an expected aspect of communal living and association with SS. This research recommends that identity can be retained with minor modifications that do not pose a risk to anyone. Forming sexual/intimate relationships may be problematic, since a woman with an ID may be

struggling to cope with a diagnosis of ID which may bring additional difficulties with sexual identity. This research suggests that women seek out and ask for help and guidance in order to help ascertain and identify their choice of sexual identity.

5. The findings from this research study propose that women with an ID may have difficulty with gender, in particular male staff involvement in their treatment. If this is to be expected then women and their families can prepare for this issue, make inroads to mitigate the ill-effects and sustain positive relationships with male role models including members of staff.
6. This research corroborates previous research which states that women with an ID are more likely to be engaged in offending behaviour than their non-ID counterparts. That said, it is noteworthy to advise those women and their families that if this is likely then services should be accessed before a crime is committed, which could then minimise harm and length of time in SS.

#### 7.4.2 Recommendations for researchers

1. Researchers conducting studies with women who have an ID will find the ethical considerations from this research study to be a useful guide when planning studies. Specifically, the distinct approach to ensuring the women were kept safe throughout the research, with a detailed plan prepared to minimise psychological distress and strategies associated to implement should a situation occur. Similarly, the ethical approval process that was required for the study to proceed was intricate and researchers need to consider this and factor it into project planning.
2. The innovative methodological approach taken in this research study included the presence of a third party/parties, without which the women could not have participated. This research maintains this is a blended approach to conducting

semi-structured interviews and a new way to hear from women with an ID, which is best described in the acronym INTREPID (interviewing using a narrative approach with a third-party present, for conducting research ethically with participants who have intellectual disabilities). It is recommended that the INTREPID approach offers a practical and ethical style to data generation with women who have an ID and require the presence of staff. Researchers who adopt this approach will find depth in the quality of data generation in the unique interview situation. Providing these methodological insights may in some way widen the opportunities for people with an ID to be included in research more than they currently are.

3. One avenue for possible further study could be research into the detrimental effects of moving the women into services away from loved ones and far away from their communities and support networks.
4. A further possibility for future research could be into the offending behaviour of women with an ID. In a classic study conducted decades ago it was shown that the prevalence of offending behaviour amongst the ID population was 35% (Walker and McCabe, 1973). Meanwhile, contemporary research is exploring offending/alleged offences in this population (Murphy and Clare, 2012). There appears to be inconsistency in the literature about prevalence, and this requires further investigation.
5. Successors to this study (which could include the researcher in this study) can take this research into account and prepare a useful guide, or a toolkit of principles, designed to help the women and their families navigate SS.

#### 7.4.3 Recommendations for staff working in Women's ID Secure Services

1. Healthcare professionals may take from this research the extent to which the women talked about families and relationships, particular their in-depth

discussion of their own families and their curiosity about the families of the nurses. The nurses avoided talking about their private lives with the best intention, namely, to avoid distress. However, at times the nurses challenged the prevailing norms by discussing their personal attachments and relationships and took opportunities where appropriate to use their own relationship experiences as a way to interact with the women and encourage them to reflect on and learn from their own experiences. This reciprocity could improve therapeutic relationships and trust, and this approach could be a consideration within the current guidance of TIC (Muskett, 2014). It is suggested that the discussion of familial relationships be channelled into a model of intervention by openly asking the staff to talk to the women about their private/family/life, as the women know they have one. A therapy group situation or one-to-one could be used, as opposed to ignoring or skirting over the issue. Not all of the women want this, but it could be used as a proactive approach to enable the women to see the world how it is and prepare them for their future lives.

2. This research has found that the nurses who worked as an HCA prior to becoming an RNLD felt better prepared for the role. It is therefore advised to those entering the profession to take up the role as an HCA prior to a nurse education programme, which supports recommendations from the Francis report (2013), and the inroads made by associate nurses that learn 'on the job'.
3. The women objected to senior figures being in the ward where there is a management structure and hierarchy. Perhaps this could be addressed in a formal way, to acknowledge the individual senior roles and responsibilities some of the nurses have and alter the discourse of power imbalance into one of acceptance and equity. Educate the women on staff responsibilities and hierarchy, also to include the women in decision making. addressing the existence of a hierarchy may help protect the nurses and the women from adverse situations prompted by necessary managerial decisions.



4. The women experienced difficulties with the men in their lives, whether it was family, boyfriends, husbands or staff members. This research suggests the notion that this difficulty is due to the limited number of positive male influences they have encountered. Since the women will continue to encounter men in services or the community, to address this issue nurses/clinicians could actively promote therapeutic relationships between male staff members and the women.
5. Nurses/clinicians could be mindful of the advice from the women as to how they wanted to be communicated with. Specific guidance was given by the women in terms of the words used, tone of voice and diction, they preferred including having a sense of humour.
6. The women have encountered a significant number of professionals, peers and family members throughout their experiences and were de-sensitised to the rotation of people in and out their lives. If the women were offered the opportunity to maintain previous relationships, this may help current relationships. This could perhaps utilise a KIT network, restricted social media platforms or an NHS intranet service.
7. An even mix of male and female staff would enhance the experience of the women, and to achieve that there needs to be an increase of male student nurses. Organisations including the NHS and higher education institutions could co-ordinate an approach to widen access and participation in pre-registration nursing (learning disability) to increase the amount of male student nurses, which would impact on the number of male RNLDs.

#### 7.4.4 Recommendations for educators

1. This research suggests that educators look at curricula content to ensure that BSc/MSc Nursing topics include co-morbidity, personality disorder, mental health, substance-misuse, relationships (including intimate) trauma and loss. This will help bridge the theory to practice gap for students and ultimately nurses.
2. A specific post-graduate module aimed at addressing the needs of women with an ID in SS, their co-morbidity and specific complex needs at Level 7 within the Advanced Nurse Practitioner pathway. A module named 'Women with an ID in Secure Services,' will prepare RNs take up the role as a RN in women's secure ID services and create a workforce that is ready.
3. Placement opportunities could incorporate a range of experiences in children's and adult services, with emphasis on addressing and managing comorbidities in childhood. As well as diagnosis, treatment and assessment interventions specific to the needs of women with an ID. Align placements to the journey of the women, on an age continuum and mirrored with complexities.
4. Students who express keen interest in women's ID secure service could be facilitated to experience placements in those areas prior to course completion, and in preparation for the role as RNLD in Women's Secure Services.

#### 7.4.5 Recommendations for future service provision

1. Appropriate support packages and service provision is crucial for the women to be discharged into community living, and suitable accommodation is scarce and delays discharge. Resources could be made available to organisations and service providers with incentives to offer appropriate services to facilitate a speedier discharge and prevent longer unnecessary stays in SS.

2. The data in this research indicates that attitudes towards female secure ID services needs to change. The nurses viewed the prospect of working in the service with trepidation and doubt and being 'moved' into the service was viewed as a punishment. There needs to be more communication, integration, and involvement between staff across all services into the women's ID secure service. If the 'men' (from secure services) play football in open spaces and are seen to be approachable, then some work needs to be done to enable the women to do the same.
  
3. The views of the women with an ID who are in SS and currently on a discharge pathway need to be included when planning service provision. A person-centred approach is needed as one size does not fit all. Some women are confident they want/do not want to live with others in the community, and discharge to a place against their wishes may be counterproductive.

**Table 15: Summary of recommendations and future implications of this study**

Area	Recommendations/Implications
Women with an ID and their families	<ul style="list-style-type: none"> <li>• Be candid with women and families about length of stay</li> <li>• Support women and their families on admission and discharge including transition to adult services – include the women</li> <li>• Guidance and orientation on group living</li> <li>• Educate the women on professional relationships from female and male staff</li> </ul>
Research	<ul style="list-style-type: none"> <li>• Learn from the ethical approval process</li> <li>• Innovative methodology INTREPID adopted in this research</li> <li>• Future research detrimental effects of moving the women away from families</li> <li>• Prepare a toolkit of principles to help the women and their families navigate SS</li> </ul>
Staff working in women's ID Secure Services	<ul style="list-style-type: none"> <li>• Therapeutic relationships could benefit from the staff team being open about themselves</li> <li>• Working as HCA prior to nurse education prepared the nurses</li> <li>• Engage the women with staff structure, hierarchy and decision making</li> </ul>

	<ul style="list-style-type: none"> <li>• Promote therapeutic relationships with female and male staff</li> <li>• Friendly staff saying/doing the right thing</li> <li>• A balance of female/male staff working in female ID SS</li> </ul>
Education	<ul style="list-style-type: none"> <li>• Disseminate the findings to BSc/MSc students</li> <li>• Curricula content of BSc/MSc on female specific topics – including comorbidity/ relationships/trauma/substance misuse</li> <li>• Bridge theory to practice gap</li> <li>• Post grad module 'Women with ID in SS'</li> <li>• Focus placements on the journey of the women</li> <li>• Give students an option placement to include women's ID SS.</li> </ul>
Future service provision	<ul style="list-style-type: none"> <li>• Offer the same opportunities to women and men whilst in SS.</li> <li>• Support packages and appropriate accommodation on discharge.</li> <li>• Change to positive attitudes for staff working in Women's ID SS.</li> <li>• Views of the women and the staff to be included in future service provision</li> </ul>

## 7.5 Challenges in the research study

There were two significant challenges encountered during the research. The first was the lengthy process associated with seeking ethical approval, which was necessary in order to approach research sites and recruit participants. Whilst securing ethical approval was factored into the method and timeline of the research study, the length of time the process took was underestimated. In its entirety, the process took eleven months. The aim of the research meant that participants were asked questions about an experience that may have been difficult for them. Similarly, the chosen methodology meant that participants may disclose or discuss sensitive matters that would need referral and further support. That said, the situation did not present itself.

The second challenge was the length of time needed to recruit participants and collect the data. It took four months to recruit the first participant, and then data collection continued for seven months. Site A swiftly identified nurses who could be potential participants, yet the issue remained around the logistics and availability of the nurses. They were working long hours, short staffed and managing very busy complex clinical areas. The offer to hold the semi-structured interview on university campus on a rostered day off was not taken by any of the nurses. On reflection this is understandable as the nurses' off-duty time is sacred and should be protected in any event. I overcame this difficulty by working around ward routines/off duties/activities, and then attended the service on evenings and weekends. I also worked spontaneously by ringing the service in the morning to check if it was convenient for me to attend that day. I respected the decision of the nurse in charge as often it was agreed to attend and other times not. This was down to the business of the day, admissions/discharges or incidents which had unsettled the ward.

Initially, Site B were unable to identify any potential participants, though this was anticipated owing to the implementation of Transforming Care Agenda and closure of in-patient secure female ID service five years earlier. It was anticipated that there would be continued support for the women in the community, which was the case, albeit in a range of environments and organisations. After a significant amount of emails, phone calls and attending the research and development office a breakthrough was found. Recruitment of participants from Site B involved working around meetings, commitments, and the agile nature of the nurse's role. It seemed that, additionally, recruiting the women from this site involved arranging a time best suited to their community living, working patterns and availability of staff to attend.

#### 7.5.1 Challenges resulting from the research design.

The challenge resulting from the research design was the limited epidemiological or demographic information established from the participants. This was a shortcoming because the presence of further data from the participants could have provided more detail in relation to their background, histories, education, and training. Although this

feature has not affected the overall findings in the study, having this additional data could have helped future research in this field.

#### 7.5.2 Challenges encountered during data generation.

The challenge during data collection was the way the participants knew each other, particularly the historical background which brought them together through a seemingly tight-knit community. Whilst the methodology was to hear the narratives from the women and the nurses, familiarity was not factored into the design of the research. Listening to participants referring to other participants was complex, especially as the nurses spoke fondly of the women and wondered what had happened to them. Similarly, the women talked about nurses from their past in terms of endearment and wondered how they were doing. It was challenging for the researcher in this study because the questions could be answered, in terms of how the women/nurses were doing and where they were now. Although confidentiality was the presiding factor and maintained throughout.

#### 7.6 Closing comments.

This research study was designed to listen to the narrative from the women and the nurses about their experiences of SS, with the intention of hearing from those that knew and had first-hand experience of SS, those that were best placed to inform the research and meet the aims and objectives. The study is an important piece of research in the field of female, ID secure services, because women with an ID in Secure Services are a distinct population who's voice needs to be heard. This research has listened to the narratives from the women and the nurses who support them. Hearing from participants about their experiences of Secure Services through semi-structured interviews, enabled their stories to be told in the way they wanted to tell it.

Perhaps when reading this thesis, interested parties will be reassured to know that the women and the nurses had a therapeutic yet friendly relationship. The lasting impression the women had on the nurses was equally as positive as the nurses had on the women, which can be best described as a 'sisterhood', with the caveat that this included male staff who had supported them.

## 7.7 Autobiographical reflection

Undertaking this research study has been the most valuable learning experience I have had in my career to date. Carrying out this research has given me the opportunity to expand the existing set of research skills I had developed from previous studies and to delve deeper into the messiness of qualitative research. Undoubtedly, conducting this research study has been the most rewarding project so far, I anticipate there is more to follow.

My professional/educational/academic journey spans over thirty years and ranges from Registered Nurse (Learning Disability) to LLB Hons [Exempting], and MSc in Academic Practice. Essentially, nurse, solicitor, and senior lecturer. This research study has enabled me to bring together my skills, knowledge, and experience from distinct intellectual areas of health, law, and intellectual disabilities. Moreover, this placed me as the researcher in this study in a position to influence the current thinking, as well as contributing to the current debates and conversations on the subject of women with an ID in secure services. Furthermore, in my role as a researcher, Registered Nurse Learning Disabilities, and educator, I am in a position to take forward some of the recommendations from this research study and continue to champion for women with Intellectual Disabilities.

Conducting this research has been a labour of love, conducted out of enjoyment and for the benefit of others, although at times the research journey was expectedly challenging, complicated, and uncomfortable, as it should be. As a result of this research, I am enlightened from the findings and now others in the field can be

enlightened also, to pass on what I have found in order to improve the experiences of women with an ID in Secure Services.

## 7.8 Chapter summary

This chapter has recapitulated the research aims and objectives, and a discussion of how this research has produced a research study that can contribute to what is already known about women with an ID in Secure Services. By discussing the findings this chapter has précised what has been found and what it means for clinical practice. Showing how the findings in the data can influence the evidence base, in that researchers will need to be cognisant of this research study in any future work. The chapter has acknowledged the limitations in the study and provided recommendations and future directions in five sections: for women with an ID and their families, researchers, staff working in secure women's ID services, educators, and service provision. The chapter has discussed the challenges encountered in the research, from the research design and during data generation, and has concluded with implications from the findings and closing comments.

And, finally, this thesis has provided an opportunity for the women and the nurses to tell their stories.



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## List of Appendices

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## **Appendix 1 Interview schedule for the women**

### **Preamble to interview:**

Good morning/afternoon my name is Angela Ridley and I am a Senior Lecturer in the department of [REDACTED]. This is in the faculty [REDACTED] [REDACTED] at [REDACTED] University in [REDACTED] then show staff ID badge.

Thank you for agreeing to find out more about the study. I expect this will take around one hour and more one and a half hours. Your participation will be anonymised. Your name will not appear.

You have been given a copy already of the information sheet for participants, and I have another copy here. You may have some questions about the information sheet or about the study. [show paper copy of PIS [patients]].

(WHEN STAFF ARE PRESENT); You have a third party/parties resent with you today. I would like to take this opportunity to verify that you are happy to proceed with the interview with this/these persons present. If you do not wish to proceed from this point, I accept this and we can stop now. When you consent to proceeding with the interview this tells me you accept the staff being present.

To the staff present, the interview is confidential for the women and will be for you. You will not be named or identified in any way. Should you feel uncomfortable at any time during the interview just ask me to stop. If you feel that you would like to talk to someone in your team or your manager about the interview let me know and I can

assist you with that. Everything that will be talked about during the interview will be confidential. If you are happy to continue then I will tell you all about the study.

About the study:

You have been given a copy already of the information sheet for participants, and I have another copy here. You may have some questions about the information sheet or about the study. [show paper copy of PIS [patients]].

The title of the study is; “An exploration of the experiences of women with an Intellectual Disability in secure services, a narrative enquiry in their own words”

The principal research question therefore is ‘What are the experiences of women with an Intellectual Disability within secure services?’ An additional exploration of the preparation, training and education of Registered Nurses working in this environment will be undertaken”

The overall aim is to explore the experiences of women with an intellectual disability (ID) within secure services: and how Registered Nurses support those women.

This study therefore aims to find out how women with an ID experience secure services and how the nurses support those women. The research will hear from the women and Registered Nurses about their experiences of residing or working in secure services.

The aims are:

1. To investigate the experiences of women with an ID who are resident within or have experience of secure services



2. To explore the preparation, practice, assumptions and experiences, which underpin the behaviour and practices of RNs who support women with an ID in secure services.
3. To uncover and analyse any enablers that are present as areas of good practice in relation to the way RNs support women with an ID

Objectives:

The objective of this research is to gain a clear understanding of the way women who have ID experience secure services and how Registered Nurses support those women. The intention is;

1. To develop innovative qualitative methodological approaches in exploratory research with female patients who have an ID and are in secure services.
2. To explore the treatment of women with ID of secure services based on the lived experiences as told by the women and the nurses.
3. To discover, through the stories of women and the nurses, the nature and provision of significant support provided or accessed for women with an ID in secure settings.
4. To find out what the nurses' perspectives are about their preparation and practice for working in female ID secure services.
5. Utilise objectives 1-4 to contribute to the body of knowledge, making recommendations for practice and service development in secure services,

associated with the care management and treatment in secure services of women with an ID.

If you agree to participate in this I will now ask you to sign the consent to participate form [paper form and signature required] the interview will be recorded and I will now turn it on if this is ok by you. The reason it is being recorded is so that I can have an exact record of what you say. The recording will be transferred into a hard drive where no one has access to other than myself. Once it is transferred the original file will be deleted from the portable device.

RECORDING SWITCHED ON

### **Prompts for narrative interviews**

The following are guided questions that are prompts for use when hearing the narratives from participants. This is to focus and to guide the narrative so that the time with each participant is maximised to elicit a full story. The prompt questions will be referred to when hearing from women with an ID.

1. Can you tell me about what led you to being here?
2. What is your experience of female secure services?
3. Can you talk me through a typical day?
4. Where are your best relationships?
5. Where do you get most support?

These questions will be guided by the main premise of;

1. How the women came to be cared for in a secure setting?
2. The history of their care management and treatment within the secure setting?
3. Their direct experience of engagement, counselling, therapy, recovery, rehabilitation, repatriation, medical treatment, restraint and/or seclusion.
4. Their direct experience of significant relationships, family contact and support and community presence and engagement, as well as exploring the concept of resilience.
5. The recognition of enablers or 'what works' that are present as areas of good practice in relation to the way RNs support women with an ID.

Closing the interview:

Thank you for your time today

The interview will now be transcribed, and I will come back to see you and ask you to check it over for accuracy. Do you have anything you would like to add before we end the recording?

Remember you can withdraw until your data is anonymised. If you have any further queries you can get in touch with me anytime on email and the telephone numbers which are on the participant information sheet.

Thank you once again for your contribution to this research study, it is appreciated.

## **Appendix 2 Interview schedule for the nurses**

### Preamble to interview;

Good morning/afternoon my name is Angela Ridley and I am a [REDACTED] in the department of [REDACTED]. This is in the faculty of [REDACTED] at [REDACTED] University. [Show staff ID]

Thank you for agreeing to find out more about the study. I expect this will take around one hour and more one and a half hours. Your participation will be anonymised. Your name will not appear.

### About the study;

You have been given a copy already of the information sheet for participants, and I have another copy here. You may have some questions about the information sheet or about the study. [show paper copy of PIS [staff].

The title of the study is; “An exploration of the experiences of women with an Intellectual Disability in secure services, a narrative enquiry in their own words”

The principle research question therefore is ‘What are the experiences of women with an Intellectual Disability within secure services?’ An additional exploration of the preparation, training and education of Registered Nurses working in this environment will be undertaken”

The overall aims is to explore the experiences of women with an intellectual disability (ID) within secure services: and how Registered Nurses support those women.

This study therefore aims to find out how women with an ID experience secure services and how the nurses support those women. The research will hear from the women and Registered Nurses about their experiences of secure services.

### The aims are;

1. To investigate the experiences of women with an ID who are resident within or have experience of secure services
2. To explore the preparation, practice, assumptions and experiences, which underpin the behaviour and practices of RNs who support women with an ID in secure services.
3. To uncover and analyse any enablers that are present as areas of good practice in relation to the way RNs support women with an ID

### Objectives;

The objective of this research is to gain a clear understanding of the way women who have ID experience secure services and how Registered Nurses support those women. The intention is;

1. To develop innovative qualitative methodological approaches in exploratory research with female patients who have an ID and are in secure services.
2. To explore the treatment of women with ID of secure services based on the lived experiences as told by the women and the nurses.
3. To discover, through the stories of women and the nurses, the nature and provision of significant support provided or accessed for women with an ID in secure settings.
4. To find out what the nurses' perspectives are about their preparation and practice for working in female ID secure services.
5. Utilise objectives 1-4 to contribute to the body of knowledge, making recommendations for practice and service development in secure services, associated with the care management and treatment in secure services of women with an ID.

If you agree to participate in this I will now ask you to sign the consent to participate form [paper form and signature required] the interview will be recorded and I will now turn it on if this is ok by you. The reason it is being recorded is so that I can have an exact record of what you say. The recording will be transferred into a hard drive where no one has access to other than myself. Once it is transferred the original file will be deleted from the portable device.

RECORDING SWITCHED ON

I will now ask you to tell me about your experiences, I have three broad questions.

Questions for Registered Nurses [RNLD/RMN]

The following are guided questions that are prompts for use when hearing the narratives from participants. This is to focus and to guide the narrative so that the time with each participant is maximised to elicit a full story. The prompts will be used when hearing from Registered Nurses.

1. How do you support women with an ID?

Activities, Typical day

2. How prepared and trained do you feel to engage and support women with an ID?

Prepared for practice CPD Formal qualifications Experience Way they work as a team Autonomous working Lone working Staff numbers Length of service MDT Psychology led Perceptions Voice Named nurse system Lived experience Attributes Personality Qualities Attitude Skills and knowledge

3. How do you feel you might develop this approach both in the short and long term?

Looking at the ideal In supporting women with ID what do you think is the ideal set of circumstances? In what scenario would best be able to function in a caring supportive capacity What exactly is the best option for training, [qualifications linked to question 2] Comments on forensic patients Components of courses gravitate to forensic environments What sort of preparation do you need? What staff experience is required for working in this environment? Normalisation Assessment of Risk MH Act Legislation Pharmacology Interventions Rapid tranquilisers LD Specific issues C and R PBS Therapeutic interventions Communication Seclusion DoLS Capacity Consent

#### Closing the interview;

Thank you for your time today

The interview will now be transcribed, and I will come back to you to check it over for accuracy. Do you have anything you would like to add before we end the recording?

Remember you can withdraw until your data is anonymised. If you have any queries you can get in touch with me anytime on email and the telephone numbers which are on the participant information sheet.

Thank you once again your contribution to this research study, it is appreciated.

### **Appendix 3 Participant Information leaflet Accessible version**



### Once you decide to take part

If you decide to take part, we will arrange two meetings to suit you. The first will be to tell you about the research. The second will be to ask some questions about your experience.



### Helping others

By giving your help with this study you will help others in the same situation.



### In confidence

Everything you tell me will be between us.

Only when we both need extra help someone else

If you have then  
I would like to talk to you about how you found the experience.

### Why I am doing this

Because I want to find out what works well and what can be better. This is to help women with a learning disability when they are in secure services. It will also help nurses who support those women.



### It's your decision

will be told, this will be done confidentially.

### If you change your mind

You can stop being part of this before the



data is made anonymous and there is no problem if you decide to stop

Each meeting may take about one and a half hours. There are no right or wrong answers, I am interested in your views, this will be put into the research report.

### At the end



You can see the final report. Then it will be made available for people to read.

People may read it to find out about secure services.

You don't have to take part if you don't want to. Nobody will mind if you say no.



### Your views count

If you do take part your views will be listened to and will be part of the report.



If you would like to take part or you have any questions you can contact me on; 0191 2156312 [a.ridley@northumbria.ac.uk](mailto:a.ridley@northumbria.ac.uk)  
You can also contact my supervisor Dr Norman McClelland on 0191 2156179/  
[norman.mcclelland@northumbria.ac.uk](mailto:norman.mcclelland@northumbria.ac.uk)



**Northumbria University**  
NEWCASTLE

My name is Angela Ridley I am from Northumbria University



Have you come into contact with secure services, or have helped someone else who has?



## **Appendix 4 Participant Information Sheet - Staff**



**Northumbria  
University**  
NEWCASTLE

Title; ‘

**“An exploration of the experiences of women with an Intellectual Disability and nurses within secure services, a narrative enquiry in their own words”.**

### **Participant Information Sheet [Staff]**

You are being invited to take part in this research study. Before you decide it is important for you to read this leaflet, so you understand why the study is being carried out and what it will involve.

Reading this leaflet, discussing it with others or asking any questions you might have will help you decide whether you would like to take part or not. Participation in this research is voluntary and there is no payment for taking part. Withdrawal from the research is possible any time before data is anonymised.

#### **What is the Purpose of the Study?**

The overall aim of this study is to explore the experiences of women with an intellectual disability (ID) within secure services, and how Registered Nurses support those women.

This study aims to find out how women with an ID experience secure services and how registered nurses support those women. The research will hear from the women and nurses about their experiences of referral, assessment, treatment, interventions and outcomes in secure services.

The study is partial fulfilment of a Professional Doctorate thesis at Northumbria University. Being completed by Angela Ridley who is The Chief Investigator (CI) of the research study. Additionally, there will be a Principal Investigator (PI) attached to the study from your NHS trust.

### **Why have you been invited?**

It is important that we talk to as many people as possible and you have indicated that you may be interested in taking part in this study. In order to take part you must be;

- Registered Nurses [RNLD/RMN] who have supported women with an ID in secure services of [REDACTED] or [REDACTED]
- Registered Nurses who are currently supporting women with an ID in secure services in [REDACTED] or [REDACTED]

Unfortunately, you will not be able to participate in this study if you are;

- A man who has an ID
- A woman who has an ID who is experiencing a mental health crisis.
- On probation

The inclusion and exclusion criteria has been applied so the research can hear from those who have experienced secure services and are best placed to give an account of those experiences.

### **Do you have to take part?**

No, you do not have to take part. It is up to you whether you take part in the study. This information sheet is to help you make that decision. You may prefer to discuss taking part with your family, colleagues or any other professional. If you decide to do this, you will be given additional time to enable you to do this. If you do decide to take part, remember that you can stop being involved in the study without saying why. You can withdraw any time prior to the point at which data is made anonymous. This is for reasons associated with the difficulty in withdrawing analysed data which has been made anonymous. You are completely free to decide whether or not to take part, or to take part and then leave the study before data is made anonymous. You are welcome to take part in the first steps of the project and choose not to take part in the research. You do not need to give reasons why you wish to withdraw. Should you decide to withdraw your data will be withdrawn, destroyed in line with GDPR and Northumbria University transparency policies.

**You will be asked to attend an informal meeting;** this can be held in your place of work or on campus at Northumbria University. This is when you will be told all about the study. If you agree to participate you will be asked by the CI to sign a consent form.

Two weeks after the informal meeting the CI will contact you. This will be to arrange your individual interview, for a time best suited to you. to arrange a time best suited to you to meet. During this interview you can tell me about your experiences. This will be informal and will be arranged for a day and time that suits you best; around your duty Rota and patient contact commitments. The meeting will take about 1 to 1 and a half hours. You can withdraw at this stage and you do not need to say why. You can withdraw because the information you have given will not have been anonymised at this stage.

With your permission the interview will be audio recorded, this is to make sure I remember everything you talk about. After this I will go through what you have told me. To do this I will send you a transcription of your interview. I will go through your account in detail and should you need additional support the CI will ensure that you receive this on a one to one basis.

### **What are the possible disadvantages of taking part?**

It is envisaged that this research will not cause harm, however due to the sensitivity and emotive subject there is the possibility that some participants may experience uncomfortable feelings, disclose sensitive information and may become anxious. Every step has been taken to minimise any likely stress or discomfort. Confidentiality and anonymity is guaranteed as well as the option to withdraw from the study at any point.

Confidentiality will need to be breached where a disclosure is made that is sensitive and may have legal implications.

Should you disclose any information that suggests abuse or is a safeguarding issue then this will be appropriately referred through the standard procedures. You will be supported and reassured that your professional development or appraisal will not be affected in any way following such a disclosure.

You may be reassured to know that the CI has many years' experience working with people who have intellectual disabilities; as well as many years' experience in communicating with

### **What are the possible benefits of taking part?**

By taking part in the study you will be participating in a study which will identify good practice and identify any areas that could be better. It is anticipated this will inform practice with the overall objective to benefit women with an intellectual disability as well as nurses.

Also, by taking part and telling us your views of the experiences of secure services you will be helping to enhance services based on the views of those that count.

### **Will taking part in this study be kept confidential and anonymous?**

Yes, your contribution will be kept confidential and your name will not be disclosed at any point, a personal code will be allocated to you as a unique identifier to ensure confidentiality is preserved throughout. All communication will be configured electronically which will allow electronic storage on the Northumbria University system which is password protected and available only to registered users. In this study there is one registered user, (myself) the Chief Investigator (CI).

The consent form you have signed will be stored separately from your other data. The data collected from you in this study will be confidential. The only exception to this confidentiality is if the CI feels that you or others may be harmed if information is not shared.

### **How will your data be stored?**

Paper data will consist of your consent form, the interview guide and the transcription of your interview. The interview guide will be used during your interview to guide the account you give to me. All paper data will be kept in locked storage. All electronic data; including the recordings from your interview, will be stored on the University U drive, which is password protected. All data will be stored in accordance with University guidelines and the General Data Protection Regulations 2018. Should you decide to withdraw prior to data analysis then your data will be destroyed in line with GDPR and Northumbria University policies.

### **How will your data be used?**

Northumbria University is the sponsor for this study based in the United Kingdom.

We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Northumbria University will keep identifiable information about you for 5 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.

You can find out more about how we use your information by contacting Angela Ridley on [a.ridley@northumbria.ac.uk](mailto:a.ridley@northumbria.ac.uk) or 0191 2156312.

Northumbria University will collect information from you for this research study in accordance with our instructions.

Northumbria University will keep your name and contact details confidential and will not pass this information to anyone else. Northumbria University will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from Northumbria University and regulatory organisations may look at your medical and research records to check the accuracy of the research study. Northumbria University will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

Northumbria University will keep identifiable information about you from this study for 5 years after the study has finished.

### **What will happen to the results of the study?**

The findings of this study will be presented to all participants in the first instance, in the form of a summary. Everyone will be asked for approval and verification of the data. Once this has been obtained and verified the research report and findings will be circulated to a wider arena. The wider area will include local environments then national areas which all support women with a learning disability in secure services. The general findings will be published in a scientific journal and at a research conference. However, the data will be anonymised and you or the data you have provided will not be personally identifiable. The findings may also be shared with other organisations/institutions that have been involved with the study.

### **Who is Organising and Funding the Study?**

The organiser and funder of this research is Northumbria University.

### **Who has reviewed this study?**

Before this study could begin, permissions were obtained from the Northumbria University, Faculty of Health and Life Sciences Research Ethics Committee. The NHS Research Ethics Committee have also reviewed the study in order to safeguard the interests of the participants and have granted approval for the research to go ahead.

### **Contact for further information:**

Chief Investigator email: [a.ridley@northumbria.ac.uk](mailto:a.ridley@northumbria.ac.uk)

Supervisor email; [norman.mcclelland@northumbria.ac.uk](mailto:norman.mcclelland@northumbria.ac.uk)

Available in the event of an emergency on 0191 2156312    0191 215 6000

or 

## **Appendix 5 Participant Information Sheet - Patients**



**Northumbria  
University**  
NEWCASTLE

Title; ‘

**“An exploration of the experiences of women with an Intellectual Disability and nurses within secure services, a narrative enquiry in their own words”.**

### **Participant Information Sheet [Patients]**

You are being invited to take part in this research study. Before you decide it is important for you to read this leaflet, so you understand why the study is being carried out and what it will involve.

Reading this leaflet, discussing it with others or asking any questions you might have will help you decide whether you would like to take part or not. Participation in this research is voluntary and there is no payment for taking part. Withdrawal from the research is possible any time before data is anonymised.

#### **What is the Purpose of the Study?**

The overall aim of this study is to explore the experiences of women with an intellectual disability (ID) within secure services, and how Registered Nurses support those women.

This study aims to find out how women with an ID experience secure services and how registered nurses support those women. The research will hear from women and nurses about their experiences of referral, assessment, treatment, interventions and outcomes in secure services.

The study is partial fulfilment of a Professional Doctorate thesis at Northumbria University. Being completed by Angela Ridley who is The Chief Investigator (CI) of this research study. Additionally, there will be a Principal Investigator (PI) attached to the study from your NHS trust.

### **Do you have to take part?**

No, you do not have to take part, it is up to you whether you take part in the study. This information sheet is to help you make that decision. You may also prefer to discuss taking part in this study with your family, carers, support staff or advocate. If you decide to do this, you may need longer to decide whether to take part or not. You will be given time to enable you to do this. If you do decide to take part, remember that you can stop being involved in the study without saying why. You can withdraw any time prior to the point at which data is made anonymous. This is for reasons associated with the difficulty in withdrawing analysed data which has been made anonymous. You are completely free to decide whether to take part, or to take part and then leave the study before data is made anonymous. You are welcome to take part in the first steps of the project and choose not to take part in the research. You do not need to give reasons why you wish to withdraw. Should you decide to withdraw from the study then your data will be withdrawn and destroyed in line with GDPR and Northumbria University transparency policies.

### **Why have you been asked to take part?**

You may have experienced secure services within the NHS for treatment or assessment. This means you are (or have been in the past) a patient within secure services. It is important that the research hears from women with an ID and the nurses who support them. You have indicated that you may be interested in taking part in this study. In order to take part, you must be;

- A working age adult woman who has an ID and has experienced secure services within ■ or ■
- A woman with an ID with capacity to consent
- A Registered Nurse who has/have supported women with an ID in secure services in ■ or ■

Unfortunately, you will not be able to participate in this study if you are;

- A man who has an ID
- A woman who has an ID who is experiencing a mental health crisis.
- You are on probation

The inclusion and exclusion criteria has been applied so the research can hear from those who have experienced secure services and are best placed to give an account of those experiences.



### **What will happen if you do take part?**

**You will be asked to attend an informal meeting;** this will be held in secure services in either [REDACTED] or [REDACTED]. This is when you will be told all about the study. After this, you can contact me anytime if you have any specific issues or questions.

Two weeks after the informal meeting the CI will contact you. This will be to answer any questions you may have, if you agree to participate, we will arrange your individual interview, for a time best suited to you. Before your interview starts the CI will ask you to confirm you would still like to participate and sign a consent form.

During this interview you can tell the CI about your experiences. This will be informal and will be arranged for a day and time that suits you best, around your commitments. This will take about 1 to 1 and a half hours. You can withdraw at this stage and you do not need to say why. You can withdraw because the information you have given will not have been anonymised at this stage.

With your permission, the interview will be audio recorded, this is to make sure I remember everything you talk about. After this, the CI will go through what you have said. To do this the CI will send you a transcription of your interview. The CI will go through your account in detail. Should you need additional support the CI will ensure that you receive this on a one to one basis.

### **What are the possible disadvantages of taking part?**

It is envisaged that this research will not cause harm, however due to the sensitivity and emotive subject there is the possibility that some participants may experience uncomfortable feelings, disclose sensitive information and may become anxious. Every step has been taken to minimise any likely stress or discomfort. Confidentiality and anonymity is guaranteed as well as the option to withdraw from the study at any point. Confidentiality will need to be breached where a disclosure is made that is sensitive and may have legal implications.

Should you disclose any information that suggests abuse or is a safeguarding issue then this will be appropriately referred through the standard procedures. You will be supported and reassured that your care or treatment will not be affected in any way following such a disclosure.

You may be reassured to know that the CI has many years' experience working with people who have Intellectual disabilities; as well as many years' experience in communicating with people in a way that avoids unnecessary stress. Additionally, the CI is able to identify any distress, to act appropriately and sensitively.

### **What are the possible benefits of taking part?**

By taking part in the study you will be participating in a study which will identify good practice and identify any areas that could be better. It is anticipated this will inform practice with the overall objective to benefit women with an intellectual disability as well as nurses.

Also, by taking part and telling us your views of the experiences of secure services you will be helping to enhance services based on the views of those that count.

### **Will taking part in this study be kept confidential and anonymous?**

Yes, your contribution will be kept confidential, and your name will not be disclosed at any point, a personal code will be allocated to you as a unique identifier to ensure confidentiality is preserved throughout. All communication will be configured electronically which will allow electronic storage on the Northumbria University system which is password protected and available only to registered users. In this study there is one registered user, which is the Chief Investigator.

The consent form you have signed will be stored separately from your other data. The data collected from you in this study will be confidential. The only exception to this confidentiality is if the CI feels that you or others may be harmed if information is not shared.

### **How will your data be stored?**

Paper data will consist of your consent form, the interview guide and the transcription of your interview. The interview guide will be used during our interview to guide the account you give to me. All paper data will be kept in locked storage. All electronic data; including the recordings from your interview, will be stored on the University U drive, which is password protected. All data will be stored in accordance with University guidelines and the General Data Protection Regulations 2018. Should you decide to withdraw prior to data analysis then your data will be destroyed in line with GDPR and Northumbria University policies.

### **How will your data be used?**

Northumbria University is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Northumbria University will keep identifiable information about you for 5 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.

You can find out more about how we use your information by contacting Angela Ridley on [a.ridley@northumbria.ac.uk](mailto:a.ridley@northumbria.ac.uk) or 0191 2156312.

Northumbria University will collect information from you for this research study in accordance with our instructions.

Northumbria University will keep your name and contact details confidential and will not pass this information to anyone else. Northumbria University will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from Northumbria University and regulatory organisations may look at your medical and research records to check the accuracy of the research study. Northumbria University will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

Northumbria University will keep identifiable information about you from this study for 5 years after the study has finished.

### **What will happen to the results of the study?**

The findings of this study will be presented to all participants in the first instance, in the form of a summary. Everyone will be asked for approval and verification of the data. Once this has been obtained and verified the research report and findings will be circulated to a wider arena. The wider area will include local environments then national areas which all support women with an intellectual disability in secure services. The general findings will be published in a scientific journal and at a research conference. However, the data will be anonymised and you or the data you have provided will not be personally identifiable. The findings may also be shared with other organisations/institutions that have been involved with the study.

The organiser and funder of this research is Northumbria University.

**Who has reviewed this study?**

Before this study could begin, permissions were obtained from the Northumbria University, Faculty of Health and Life Sciences Research Ethics Committee. The NHS Research Ethics Committee have also reviewed the study in order to safeguard the interests of the participants and have granted approval for the research to go ahead.

**Contact for further information:**

Chief Investigator email: [a.ridley@northumbria.ac.uk](mailto:a.ridley@northumbria.ac.uk)

Supervisor email [norman.mcclelland@northumbria.ac.uk](mailto:norman.mcclelland@northumbria.ac.uk)

Available in the event of an emergency on;

0191 2156312    0191 215 6000

Or [REDACTED]

## Appendix 6 Consent form

### Consent Form for all Participants

Project Title:

**“An exploration of the experiences of women with an Intellectual Disability and nurses within secure services, a narrative enquiry in their own words”.**

Chief Investigator: Angela Ridley

*please tick or initial where applicable*

I have carefully read and understand the Participant Information Sheet - Version 4.	<input type="checkbox"/>
I have had an opportunity to ask questions and discuss this study and I have received satisfactory answers.	<input type="checkbox"/>
I understand I am free to withdraw from the study any time before my data is analysed. Without having to give a reason for withdrawing, and without prejudice. My data will be destroyed.	<input type="checkbox"/>
I have been given information about the study in a way that I can understand	<input type="checkbox"/>
I have decided I need more information	<input type="checkbox"/>
I agree to take part in this study.	<input type="checkbox"/>
I understand that by taking part in the study I could be exposed to situations that may generate some psychological distress, which become apparent during and/or after the study has finished. I accept the small risk of experiencing psychological distress as part of this research	<input type="checkbox"/>

I hereby confirm that I give consent for the following recordings to be made, I understand that the recording(s) may be referred to and published in an appropriate journal/textbook or on an appropriate Northumbria University webpage. My name or other personal information will never be revealed.

Recording	Purpose	Y/N
voice recordings	For recording interview, so narratives can be fully transcribed, and a true account is given	

I understand that relevant sections of my [medical records] and data collected during the study may be looked at by responsible individuals from the NHS Trust or from regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

Signature of participant..... Date.....

(NAME IN BLOCK LETTERS).....

Signature of researcher..... Date.....

(NAME IN BLOCK LETTERS).....

## **Appendix 7 Abstract for conference**

**Presentation title; A *progress report on Doctoral research focusing upon an exploration of the experiences of women with an Intellectual Disability in secure services, a narrative enquiry in their own words***

### **Background**

The Bradley report (2009) set the direction of travel for supporting people with intellectual disability (ID) in the criminal justice system (CJS) and recommended collaborative working schemes to best to serve the ID population. Bradley (2009) also recommended further research, training and ID awareness to be developed in conjunction with service users. The Talbot review (Loucks 2007) stated that the prevalence of ID in the offending population remains unclear; however, the review suggested that what is clear is the impact of an ID on a person's ability to cope with the CJS, suggesting that a person with an ID is at greater risk of re-offending. In addition, this review indicated that research into specialist services can be problematic but should not be avoided.

### **Objectives**

This presentation will relate how secure services support people with an ID who may have experienced the CJS, have a health need, and require conditions of security. The work focuses upon women with an ID who have previously accessed, or are currently accessing, secure services, and Registered Nurses who have supported and/or are supporting the service users. Twelve women (service users) and twelve registered nurses from secure settings in two North East areas have been invited to participate in the study. This is a study that recognises how little research has been undertaken with women with an ID, with there being a similar picture amongst nurses who support them in secure services. The purpose of the research study is to determine how women with an ID experience secure services, and how registered nurses (RNs) support those women, illustrating how an innovative methodology (narrative enquiry) is adapted and utilised in the research study. The data will have been gathered at time of presentation and analysis will have taken place. The presentation will also have a focus on the ethical nature of this type of research, an essential consideration for researchers involved in such work.

18<sup>th</sup> International Conference on Offenders  
with an Intellectual and/or Developmental Disability

**Northumbria University**  
NEWCASTLE

10-11 April 2019 Birmingham Events and Conference Centre  
Angela Ridley

Program report on Domestic research by Angela Ridley

This seminar will...

- Provide delegates with a progress report on partial fulfilment of a Doctoral research study.
- The research study is an exploration of the experiences of women with an Intellectual Disability in secure services, a narrative enquiry in their own words

Program report on Domestic research by Angela Ridley

Additionally,

- This seminar will show how the research study explores the experiences of women with an ID, who may have experienced the CJS, have a health need, and require conditions of security.
- The work focuses upon women with an ID who have previously accessed, or are currently accessing, secure services, and Registered Nurses who have supported and/or are supporting the service users.

Program report on Domestic research by Angela Ridley

The principle research question is ;

‘What are the experiences of women with an Intellectual Disability within secure services?’ An additional exploration of the preparation, training and education of Registered Nurses working in this environment will be undertaken”

This is a study that recognises how little research has been undertaken with women with an ID, with there being a similar picture amongst nurses who support them in secure services.

Program report on Domestic research by Angela Ridley

The objective of this research is to gain a clear understanding of the way women who have ID experience secure services and how Registered Nurses support those women. This study will;

- Further develop methodological approaches in exploratory research with female patients who have an ID, exploring and developing qualitative methodological approaches
- Explore and deliver care management and treatment recommendations based on the shared experiences as related by women with an ID themselves.
- To examine/ explore the nature and provision of significant other/ family and community support provided or accessed for and on behalf of women with an ID in secure settings
- To explore the development and provision preparation for practice for RNs working in secure services
- Utilise objectives the above to contribute to the body of knowledge, making recommendations for practice and service development in secure services, associated with the care management and treatment in secure services of women with an ID.

Program report on Domestic research by Angela Ridley

Why?...

The Bradley report (2009) set the direction of travel for supporting people with intellectual disability (ID) in the criminal justice system (CJS) and recommended collaborative working schemes to best serve the ID population. Bradley (2009) also recommended further research, training and ID awareness to be developed in conjunction with service users.

The Talbot review (Loudes 2007) stated that the prevalence of ID in the offending population remains unclear; however, the review suggested that what is clear is the impact of an ID on a person's ability to cope with the CJS, suggesting that a person with an ID is at greater risk of re-offending.

In addition, this review indicated that research into specialist services can be problematic, but should not be avoided. Equally, there are areas of good practice that need shining.

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Prevalence

Diagnostic tools and processes vary which makes numbers difficult to determine, specifically of how many offenders have an ID (Loudes 2007 p11) ‘the most consistent thing in the most inconsistent information about the number of offenders with learning difficulties or learning disabilities is that no one agrees on how many exist’.

Talbot (2012) a plausible yet disproportionately high estimation for LD in the adult offender population is about 5-10%.

Nationally, there are between 8 and 10% of patients in medium secure settings who are women (Dent 2006). This figure is four times as many as in 1995 (Hassell & Bartlett 2001). Whilst this is a minority population, women in secure health settings lose their liberty for four times longer than women in prison and for longer than men in secure health (Aitken & Logan 2004).

Program report on Domestic research by Angela Ridley

Prevalence continued

Glover and Brown (2015) analysed data collected from a national census of psychiatric inpatients with ID and autism.

The census was carried out on 30<sup>th</sup> September 2013 to identify a patient with an ID or autism.

42% of all patients were detained and a further 31% detained within the meaning of MHA Part III.

Program report on Domestic research by Angela Ridley



## Women

- Vulnerable women have been fairly placed on the agenda (Coxon 2007)
- A decade on Coxon (2007) reported that progress had been made regarding services and provision
- Haddadman (2010) stated that some progress has been made since Coxon (2007), however, Alexander et al (2010) argue that the well-intentioned developments have not been fully actioned supporting the notion that the evidence base is limited and to some extent dated. Organisations continue to evolve the limited evidence base.
- Women in Secure Hospitals (WISH) and Women's Mental Health Networks (WMHNN) are launching a new led campaign to address issues affecting women and update the evidence.

Diagram taken from research in progress

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## Harty et al (2012)

conducted a mapping exercise as part of a pathway study of women in secure services in England and Wales. The study explored the extent and range of secure service provision. It was identified from the study that there were 589 medium secure beds, 46 enhanced medium secure beds and 990 low secure beds for women nationally. The majority (309 52%) were in the NHS, under half (280 48%) were in the independent sector. Provision of low secure beds has a severe trend: 745 73% in independent sector and 254 (29%) in the NHS.

Diagram taken from research in progress

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## Women...

- continue to represent 1% of the prison population (Ministry of Justice 2014 (MoJ)),
  - despite the concerns from Coxon (2007) around women securing short imprisonment sentences; in 2013 there were 77% of women given custodial sentences compared with 63% of male offenders (MoJ 2014).
- The No One Knows programme (Lewicki 2007) estimates that 20% to 30% of offenders have learning difficulties or learning disabilities that interfere with their ability to cope within the CJ system.
- It is known that there are hidden disabilities amongst the offending population that adversely affect their ability to achieve in education and employment (Rack 2005). A woman with an ID may have learnt over time to disguise her disability. It is therefore clear that women with an ID in the CJ system are a small, distinctive population.

Diagram taken from research in progress

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## Scant provision

In-patient ID services for women are rare, therefore, if treatment is required in a secure setting, women are often placed long distances from home, family and friends, and commonly for long periods. (Alexander et al 2010). On the whole, women with a dual diagnosis of ID and mental illness are affected by longer stays in secure settings (Long & Dolby 2012).

Women make up an estimated 23% of the overall population in secure mental health (Alexander et al 2010).

Specialist service provision for women with an ID is insufficiently provided, there is a lack of evidence based interventions and treatment (Coid et al 2000).

Diagram taken from research in progress

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## Methodology

Narrative research was classically described as a method of representing an associated collection of events more recently, it is described as a spoken or written account given by people about people. Narrative research provides a thorough methodological tool to a researcher who is investigating the diversity of human experiences. This research will adopt a narrative approach because it will enable the researcher to hear from participants.

- See (Webster 1966), (Friedman & Holloway 2010).

Diagram taken from research in progress

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Twelve women (service users) and twelve registered nurses (RNs/RNDs) from secure settings in two South East 2013 Foundation Trusts as participants in the study

### Inclusion criteria

Working age (18-65) adult women with an ID  
A woman with an ID with capacity to consent  
Male and female Registered Nurses who have supported women with an ID in secure settings  
Male and female Registered Nurses who are currently supporting women with an ID in either

### Exclusion criteria

A man who has an ID  
A woman who has an ID who is experiencing a mental health crisis  
A person who is on probation

Diagram taken from research in progress

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## Challenges

There are a number of methodological challenges when participants have an ID, consideration needs to be given to the issue of a potential prior audience.

A person with an ID may not have had an opportunity to speak about their experiences. It could be argued that the researcher could be on the side of people with an ID or the oppressor (Thomas 1990) has postulated concepts of advocacy and the need for researchers to support people with an ID, so having been oppressed.

Conducting qualitative research enables access to the experiences of groups who lack the power to make their voices heard. People with an ID have something to say which is of value and experiences that are worth understanding.

This then makes this a low-risk study of secure situations, particularly in the methodological challenges involved in recruiting the group (Snel 2008).

Diagram taken from research in progress

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## The power of narratives

People tell stories or narratives, every day. Using a narrative approach in research allows a participant or speaker to tell their story. The researcher does not find narratives, but facilitates in creating the narrative (Farrington 2008).

This approach facilitates a participant to tell the researcher what happened to them. In essence, the researcher listens from the participant.

A participant constructs events into a sequence that is meaningful for their action and for the meaning that the participant wants the listener to take away from the story. Adopting a narrative approach will enable a participant to talk about events perceived by them as important.

These important events can then be evaluated in a meaningful way, by making sense of the narrative through analysis and description.

Diagram taken from research in progress

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## Keeping people safe

There are a number of ethical issues to consider with this research study. Half of the participants are women with an ID who have an accompanying carer present, which raises ethical dilemmas as well.

This is because women with an ID have impaired understanding ability as well as additional complex needs, for example reduced sensory ability. Working with this group is not straightforward, it is widely accepted that a woman with an ID may experience in certain situations.

Therefore, a great deal of care and attention is needed to consider and deal with the ethical implications of this research. Indeed Toller-Town (2008) mentions that it would be unethical to disregard people with ID from research that could distribute weight into their experiences and help shape positive care in the future.

Report approved by Research Ethics Committee on 14/09/2016

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## Ethical approval

- NIU Ethical approval
- IRAS

- 10 sessions
- Discussion
- P11, P12, P13, P14, P15, P16, P17, P18, P19, P20, P21, P22, P23, P24, P25, P26, P27, P28, P29, P30, P31, P32, P33, P34, P35, P36, P37, P38, P39, P40, P41, P42, P43, P44, P45, P46, P47, P48, P49, P50, P51, P52, P53, P54, P55, P56, P57, P58, P59, P60, P61, P62, P63, P64, P65, P66, P67, P68, P69, P70, P71, P72, P73, P74, P75, P76, P77, P78, P79, P80, P81, P82, P83, P84, P85, P86, P87, P88, P89, P90, P91, P92, P93, P94, P95, P96, P97, P98, P99, P100, P101, P102, P103, P104, P105, P106, P107, P108, P109, P110, P111, P112, P113, P114, P115, P116, P117, P118, P119, P120, P121, P122, P123, P124, P125, P126, P127, P128, P129, P130, P131, P132, P133, P134, P135, P136, P137, P138, P139, P140, P141, P142, P143, P144, P145, P146, P147, P148, P149, P150, P151, P152, P153, P154, P155, P156, P157, P158, P159, P160, P161, P162, P163, P164, P165, P166, P167, P168, P169, P170, P171, P172, P173, P174, P175, P176, P177, P178, P179, P180, P181, P182, P183, P184, P185, P186, P187, P188, P189, P190, P191, 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## **Appendix 9: Reflection from conference**

Reflective account of presenting at an international conference. For the purposes of this reflection, I will utilise Gibbs model (1998). I am utilising this model for two reasons. First, because the model allows description, evaluation of an experience to enable a reflexive practitioner to make sense of an experience. The second reason is because I have used it in the past which means I am familiar with the stages. When I have used it in the past, I have found it to be beneficial in terms of my professional development and personal effectiveness. Relating the Gibbs model means I can systemically examine the experience with the greatest benefit.

### **Description**

This account is a reflection of my presentation at an international conference. The conference was the 18<sup>th</sup> International Conference on Offenders with an Intellectual and/or Developmental Disability. It was held over two days on 10 and 11 April 2019 at Birmingham Conference and Events Centre. This forum provides a crucial platform for greater collaboration, helping professionals to share information and best practice. With an established excellent reputation for being both high quality and good value for money. The organisers of the conference are Caring Solutions Ltd and the National Autistic Society. Northumberland Tyne and Wear NHS Foundation Trust and Tees, Esk and Wear Valleys NHS Foundation are partners of the conference. The event is aimed at professionals and academics working in the field of offenders with an intellectual and/or developmental disability, including autism. The conference provides the latest thinking from eminent international speakers as well as hearing from smaller scale research and innovations in the current sessions. Concurrent sessions included treatment approaches, best practice, restraint and

PDA. The Journal of Intellectual Disabilities and Offending Behaviour (JIDOB) available through Emerald Publishing, is associated with the conference. There were three activity streams and seven concurrent sessions available. Delegates could decide on the day which one to attend. My presentation was scheduled for concurrent session four in stream B on day two at 11:00 to 12:00. The sessions occurring simultaneous to mine was: '*Communication challenges for children and adults with intellectual disabilities during cross-examination; a systematic review*' by Joanne Morrison of Tizard Centre, University of Kent, and '*Identification and Management of Pathological Demand Avoidance in a Community Forensic Setting*' by Farooq Ahmad, Rachael Mackinlay and Paul Yarnold of Birmingham Community Healthcare NHS Foundation Trust.

### **Feelings**

Half an hour before the session began, I was feeling a sense of low level anxiety. I was thinking about the delegates that may or may not attend my session. I was concerned that initially no one would come into it. Convincing myself that no one would attend because they did not think I was credible. Conversely, I was worried that scores of people would attend. Both perspectives filled me with trepidation, in that; my credibility would be in question, my subject area would be dismissed as not valid, and my methodological approach would be deemed as being inappropriate. I was also troubled about what types of delegates would they be. Ruminating about whether the international experts presenting keynote speeches would drift in by mistake, then proceed to ask me difficult questions that I could not answer. At the start of the session, I was a little less anxious but feeling uneasy nevertheless. I introduced myself and explained that I was suffering from imposter syndrome. During the session I was feeling much more confident which in turn made me feel more

proficient. At the end of the session, I felt a degree of satisfaction and overall sense of achievement.

### **Evaluation**

To evaluate the session from my perspective I think it progressed fairly well. The reason I say that is because that my initial anxieties were unsubstantiated. I feel my performance was informed and professional. There was capacity for twenty-five delegates to attend this concurrent session, I had fourteen. One of which included Dr Colin Dale, Chief Executive of Caring Solutions Ltd and the Conference Lead. The other attendees included an even spread of clinicians and academics as well as a significant amount from secure services for women with intellectual disabilities. The delegates gave me a warm reception, nods of approval and a sense of agreement was evident throughout. One delegate in particular gave me some constructive feedback, which included tips and suggestions about recruiting participants. One thing that was negative about the session was the room. There was no natural light, and it quickly became warm and little uncomfortable. The screens were not big enough for those at the back to see clearly. I prepared the PowerPoint ahead of the conference for the organisers. I also had with me an annotated version with additional information for my purposes (see attached). On evaluation of this the annotations I made were too much and some were pertinent and should have been included as a side.

### **Analysis**

What may have helped my presentation was if I had the opportunity to book the room personally or have a level of control over the location. The logistics of such an event are down to the location which in this case was the BCEC. I can make sense

of the situation by applying what I have learnt from this experience and take forward in my continuing doctoral studies. What may have helped my presentation is if I was more confident in my area, I was presenting about progress, this included ethical dilemmas and pragmatic solutions. Although I did feel very knowledgeable, even experienced in ethical considerations and the associated systems and hurdles to overcome. One delegate came up afterwards to ask me about a particular point in the NHS approvals process.

### **Conclusion**

On reflection I could have prepared more by reading more of the Journal of Intellectual Disabilities and Offending Behaviour. This is linked to the conference and the experts attending the conference are contributors. In conclusion I feel that as my research data grows, my writing continues and my thesis begins to take shape, will all enable me to succeed in the doctoral journey. I think this in turn will give me the confidence in the subject, without feeling like an imposter and to be 'one of the experts' at the conference.

### **Action plan**

Since this presentation was a progress report on doctoral research, I am anticipating that I will be accepted to present the findings from the study at a future conference. Should this take place then I will be more prepared, I will do a run through to a group of peers to 'test drive' the session. I will actively encourage comments, complaints, criticisms and compliments. This will ultimately improve in my skills, knowledge and ability as well as reducing that low-level anxiety I experienced before this one. I think that this experience will prepare somewhat to submit a paper to the journal

associated to the conference. This experience has helped me defend my decisions throughout my research journey, which will help me in the viva examination

## **Appendix 10: Timeline for ethical approval**

Date	Activity	Outcome
19/12/17	New Principal Supervisor (PS) allocated	Liaised with PS and discussed protocol
24/1/18	First supervision meeting with PS	Worked through comments with PS, new Gantt chart submitted and request for extension made, and commencement of monthly meetings
20/2/18	IRAS documentation	Worked through comments from PS
13/3/18	PS approved IRAS documents	Submitted Internal IRAS
28/3/18	PS approved final IRAS	Submitted for internal approval
2/5/18	Internal IRAS approved by FPVC IRAS submitted	Date given for REC committee for 21/5/18
21/5/18	AR and PS attended REC	No decision given on the day, a letter will be sent outlining the issues
5/6/18	Response letter received	Provisional outcome pending changes to submission
11/6/18	Met PS to go through REC comments	Work through revisions
19/6/18	Met PS went through revised documents	To complete/ re submit
2/7/18	Revised documents returned to IRAS	Further REC [sub-committee] to be held
6/9/18	Letter received from IRAS REC sub committee	Requested more amendments
18/9/18	Response to REC subcommittee sent with revised documents	REC subcommittee held
5/10/18	Approval letter received from IRAS, Favourable opinion	Submitted HRA request forms to NHS trusts
11/10/18	HRA requested further information	Submitted and returned
1/11/18	Met PS and new plan agreed	HRA contacted for approval



5/11/18	HRA and HCRW gave permission to proceed to trusts.	Contact R and D in NHS trusts as the first trust to receive notification from HRA HCRW
12/11/18	Research Passport approved and signed by PS and HR department University	Sent to NHS trusts Submitted non-substantial amendment form internally and HRA as the original dates applied for in IRAS documentation had lapsed
29/1/19	Letter of Access issued by NHS	Contact with Service Managers for recruitment
February, March 2019	Service Manager from NHS trust shared study information to patients and staff for potential participants Service Managers unable to identify potential areas for recruitment NHS	Recruited nurses and interviews conducted in *NHS trust target of 6 nurses from NHS trust achieved Meetings with NHS R and D to recruit patients
March April May 2019	Recruited nurses NHS	Target recruitment of 6 nurses from NHS achieved
May June 2019	Recruited patients NHS	Interviews carried out target of 6 patients from * NHS achieved
June July 2019	Recruited patient's NHS/P	Target of 6 patients from * NHS not achieved, recruited 3 patients
August 2019	Met with all participants to work through transcriptions	One withdrawal patient from NHS

## **Appendix 11: Strategies to minimise risk to participants**

<b>Potential risk;</b>	<b>What the risk is</b>	<b>Strategies to minimise the risk</b>
<b>Being a participant</b>	Failure to maintain security	<p>Arrange meetings at an agreed place either on campus or mutually agreed venue</p> <p>Hold interviews during normal working hours</p> <p>Have contact details to hand of campus services in case of emergency</p>
<b>Being a participant</b>	Undue stress, loss of self-esteem or psychological injury	<p>Consent to participate is an ongoing process</p> <p>Opportunity to withdraw is reminded at each stage</p> <p>At introductory meeting take time to explain the what the research involves</p> <p>Explain what to expect during each stage</p> <p>Offer a comfort break during the interview</p>
<b>Being a participant</b>	Unrealistic expectations	<p>Reassure participants of their involvement and what is expected and expected risks</p> <p>Provide participants with the outcomes at the introductory stage</p> <p>Opportunity to ask questions encouraged at every opportunity</p>
<b>Being a participant</b>	Misunderstanding due to an ID or learning difficulty for example dyslexia or dyspraxia	<p>Ensure clarity of information is sent to gatekeepers</p> <p>Find the most appropriate medium of communication; engage with carers and advocates for information to prepare ahead of interview [e.g. Makaton level]</p> <p>Provide information sheet in Easy Read version</p> <p>Take time to explain the research study in detail at introductory meeting</p>

		Offer opportunity to ask further questions at any stage
<b>Being a participant</b>	Undue stress or psychological harm/personally affected by a situation	Ensure support plans are followed Re visit consent to participate
<b>Intrusion</b>	Potential harm by virtue of participation	Protect the interests of the participants by being respectful and dignified  Include carers advocates or support workers in a person-centred approach to ensure the research has integrity and conducted to acceptable professional standards
<b>Intrusion</b>	Current treatment or care plans	Ensure there are no conflicting demands on time
<b>Intrusion</b>	Logistical difficulties	Liaise with carers to avoid clashing other obligations
<b>Intrusion</b>	Full case file and workload	Flexible when the interview will take place

## **Appendix 12: Recruitment process**

All versions of the Participant Information Sheets (PISs) (Appendix XXX) were sent electronically, and paper copies given in person, to the Senior Manager for Research Innovation and Clinical Effectiveness Research and Development Departments at both study sites. Gaining access to recruit participants involves going through senior figures, gatekeepers or even a hierarchy of gatekeepers (Hood *et al* 1996) and in some instance's tiers of management (Lennox *et al* 2005). This was to facilitate links and enable appropriate and necessary permissions with regards to access and identification of Clinical Service Managers (CSMs) and a process of cascading information about the research study to the relevant clinical areas within each trust. The Research and Development Managers then contacted Clinical Service Managers via the Clinical Business Unit (CBU) monthly meeting. This process enabled the identification of a named individual within each trust, who would then act as the link person between myself as the researcher and each study site. This meant the researcher was then able to liaise directly with each study site to recruit participants.

The link person was then asked to pass on names of potential participants so they could then be contacted in person, with an intention to discuss the research in detail. Moreover, a potential participant could then contact me directly as all the PISs provided the contact details. Barriers to recruitment in the research process has been identified as problematic (Lennox *et al* 2005), additional strategies to recruit participants were shown to be effective.

Introductory meetings were arranged as part of the recruitment process, to give all the information to a potential participant. This meant an informed decision could be made about whether to take part or not. Crucially, this activity took place before a participant was asked to consent to take part.

### **The women**

The introductory meetings with the women were arranged through the designated link person from each of the study sites as part of the recruitment process. For the women this included liaising with the wider members of the multi-professional teams who were involved in supporting the women, thus known to them. This included Psychology, Occupational Therapy, Speech and Language therapy, Responsible Clinicians and Community Teams. Meetings were planned to last a minimum one hour, maximum one and a half. The purpose of the introductory meeting was to explain fully to the women who were interested in the study, what the study was about and what her involvement would be. This provided an opportunity for face-to-face introductions, and to allow a potential participant to find out what the study will entail. The researcher was also able to ascertain any additional needs, requirements or reasonable adjustments needed for anyone who would be participating in the study. support was required by one of the women when she disclosed her learning difficulty in the form of dyslexia. Strategies were used to support this by producing information in the accessible format appropriate for a person with dyslexia. This took place at a time to suit the needs of the women and in their own environment, with staff present where necessary. Organised around any therapy sessions or appointments they may have. This was important to consider at this point, the fact that some potential participants required their introductory meeting with staff present where necessary, for example a participant who was detained within the meaning of

the Mental Health Act. Additionally, there were restrictions to consider for some of the women since there was restrictions placed upon them in terms of observation. In essence this meant that staff had to be observe them at all times, this included one staff or in some cases up to three. The introductory meetings formed part of the recruitment process to give all potential participants an opportunity to hear about the research, what their involvement would be and decide whether to take part or not. This stage in recruitment took place before consent to participate was given. All introductory meetings took place within a secure ward or the home of the women.

### **The nurses**

The introductory meetings with the nurses were planned and organised via email, over the telephone or following the team meeting. This was to enable the nurses to read the PIS at a time best suited to them individually and meetings arranged around off duties, clinical responsibilities and rest breaks. An additional opportunity for the nurses was given to meet in either their place of work or in the University campus. This option was given to enable the nurses to contribute to the research in a manner that would not hinder their clinical responsibilities. An approach that would best facilitate a participant to talk candidly during the semi-structured interview. More importantly to be able to focus on the interview rather than the potential of clinical responsibilities taking priority on their time. What was important to consider here was the opportunity to contribute to the research study in a neutral environment. However, the researcher was mindful of the fact that this option may mean the nurses would be coming on to campus for their interview during their off-duty hours. Therefore, asking the nurses to give up some of their personal time for research

purposes may not have been a realistic option. All be it the option was made available, nonetheless was not accepted by any of the nurses.



## Appendix 13: Additional tables

Table 16: Acronyms used in this thesis and the full meaning

Acronym	Full meaning
ID	Intellectual Disability
PWID	People/person/patient/adult with Intellectual/Learning Disability
The women	Women with Intellectual Disability in Secure Settings who were participants
The nurses	Registered Learning Disability Nurses working in Secure Settings who were participants
RNLD	Registered Nurse Learning Disabilities
SS	Secure service(s)
MH	People with Mental ill Health
CJS	Criminal Justice System
ASD	Autism Spectrum Disorder
TIC	Trauma Informed Care

DBT	Dialectical Behaviour Therapy
RODBT	Radically Open Dialectical Behaviour Therapy
PBS	Positive Behaviour Support
PD	Personality Disorder

**Table 17: Codes generated from step 2 analysis – the women**

	The women Q1	Q2	Q3	Q4	Q5
	<b>Can you tell me about what led you to being here?</b>	<b>What is your experience of female secure services?</b>	<b>Can you talk me through a typical day?</b>	<b>Where are your best relationships ?</b>	<b>Where do you get your most support?</b>
6.	Prison/young offenders	Same/different	Activities	Staff	The ward
7.	Multiple placements	Staff male/female	Male/female	Male/female	The nurses
8.	Long way from home	Negative	Typical day or not	Other patients	MDT
9. MDT	Trauma	Positive	Family contact	Family	Male/female
10.	Index crime	Physical health	Choice	Best place/The ideal	Crime
11.	Vulnerability in relationships/bullying	Detainment /seclusion/restraint	Friendships/peers	None	Advocacy
12.	Comorbidities	Activities	STAFF PRESENT AND CONTRIBUTED	Independence	Incidents
13.	Labelling/diagnosis	Independence		Activities	Diagnosis
14.	Sexuality	Home		Future proofing/advice	Everyone is happy
15.	Multiple assessments	Family		STAFF PRESENT AND CONTRIBUTED	Medication
16.	Physical health	STAFF PRESENT AND CONTRIBUTED			Future/advice
17.	medication				Students

18.	Treatment				STAFF PRESENT AND CONTRIBUT ED
19.	Engaging with treatment				
20.	Non-engagement				
21.	Working towards leaving secure services				
22.	Women's insight into issues				
23.	Did not know what to do with her				
24.	Engagement with the law				
25.	Relationships				
26.	STAFF PRESENT AND CONTRIBUTED				

**Table 18: Codes generated from step 2 analysis – the nurses**

	Q1	Q2	Q3
	<b>How do you support women with an ID</b>	<b>How prepared and trained do you feel to engage and support women with an ID</b>	<b>How do you feel you might develop this approach both in the short and long term?</b>
1	Possession of staff and the women	Possession	Future proofing
2	Trauma	Learning on the job-in at the deep end	Legitimacy
3	Diagnosis	Further training	MPW
4	Medicalisation	Transient workforce	National /professional recognition
5	Models of nursing care	The right person for the job	Implementing /driving change
6	New ways of	Friendly staff	Improved staff

	working		support – evidence based
7	Mental health	Discharge planning	Role modelling
8	Staffing levels	Saying the right thing- and what not to say	Myth busting
9	IPW/MPW	Creating the right atmosphere	Risk/person centredness
10	Engagement	Nurses as collaborators/ the women in charge	Physical health
11	Terminology	Career trajectory	Being candid
12	Long term patients	Documentation	Authentication
13	Treatment	Female/male	Female/male
14	Treatment and risk	Ways of working, interventions/models	Discharge planning
15		Staff support	Transforming care
16		Making a home	Trauma informed care
17		Parenting/families	Nurse associate
18		Decision making/MDTs	Relationships
19		Attributes – the nurses	Idealism
20		Dealing with Disclosures	Supporting learners
21		Violence and aggression	Future courses
22		Perceptions of others	Comorbidities
			Women's issues
			Innate characteristics – you just know
			Emotional intelligence
			Celebrating Christmas/or not
			Violence/aggression
			Happy staff
			Trauma
			Protective factors
			Diagnosis

**Table 19: Candidate themes from step 3 – the women**

Objective 1 boxes shaded grey

Objective 2 boxes shaded blue

Objective 3 boxes shaded green

Objective 4 boxes shaded orange

	The women Q1	Q2	Q3	Q4	Q5
	Can you tell me about what led you to being here?	What is your experience of female secure services?	Can you talk me through a typical day?	Where are your best relationships?	Where do you get your most support?
1	<b>Historical involvement:</b> Multiple placements, placed a long way from home, removed from family home and placed into children's services participants also talked about transitioning from children to adult services, a range of secure wards and extensive lengths of time in each placement. Some participants talked about being admitted to young offenders' prisons reference their diagnosis was included in responses. Countrywide placements told me that geography played a big part in their journey. An extensive level of knowledge around low/medium/high secure wards was evident.	<b>Same/different:</b> Comparisons made between experience in children's service with that of adult services. More freedom was given in children's service there was male and female staff as well as patients in children's ward. Acquiring more things on children's wards in adults' things taken away. Participants described it as weird moving from mixed staff/patients to all females.	<b>Activities:</b> Structured daily routine began early morning with extensive plans for weekdays. Daily living activities included then choice of attending a particular session in or out the ward. Weekends more relaxed. Activity centre accessed, keeping busy to eliminate boredom therapies included as well as ad hoc time at the women's choice. Hospital discos fitness classes and out in the car. Personal care was a significant factor and having a contraband key meant the women could shave their own	<b>Staff:</b> Staff on the ward, named nurse care team, CPAs, girlfriend and Mother as well as former patients.	<b>The ward:</b> Ward staff the whole team and peers, there is freedom here not like prison. the ward helps better than prison did. The named nurse, 1 to 1s to discuss privately going to any staff who are on the floor. The women understood the nurses had a job to do and acknowledged they couldn't knock on the office door all the time; they would go to staff on the floor. Ward rounds, CPA, MDTs. Staff are excellent at listening  This colour code indicates the theme is aligned to objective 2

	Light green shaded box indicate theme is linked to objective 3		beard any time they wanted.		
2	<b>Prison/young offenders:</b> Index crimes and the decision to avoid giving details of certain crimes committed. Engagement with the criminal justice system and police involvement. Did not know what to do with the woman and couldn't decide what was the best place for support.	<b>Male/female:</b> Male and female staff in children's service and in school always going to male in both. Choosing male staff because wouldn't know how to talk to them and didn't trust them. All female staff in female ward was unfavourable, a mixed ward would be better. Preferring male staff compared to talking with Father.	<b>Male/female;</b> No particular preference expressed although clear that female only staff could assist with personal care. Male staff only in MDT, would need courage to ask male staff for help.	<b>Male/female</b> One particular male nurse had a very positive relationship with the women, staff supportive of same sex relationships with the women. Like/dislike of particular male staff and the women purposely disclosing personal issues to cause male staff embarrassment.	<b>The nurses:</b> Reassurances given by the nurses most help given by the named nurse. The nurses knew when the women were anxious or panicky and gave support accordingly. Similar age between the nurses and the women were noted to be a positive aspect. The women wanted to see more of the nurses especially on high days not just routine interventions. Objectionable to the decision by the manager that the nurses couldn't leave the ward. The women knew the nurses were really passionate about their job, remarked at the change in nurses every six months had its pros and cons but it generally

					unsettles the women making them more anxious.
3	<b>Trauma:</b> Victims of abuse and subsequent trauma linking this to thinking emotionally.	<b>Negative:</b> Negative experiences in relation to restrictions placed upon the women, specifically observations, restraints, seclusion, leave and lack of freedom. Everything locked and having to live by rules and regulations	<b>Typical day:</b> No typical day good days are great and bad are messy there is not an in between. A good day means no incidents no one shouting, you can talk to people and feel safe.	<b>Peers:</b> Positive relationships with other patients on the ward maintained 5 years later. An understanding of peers MHA status and an appreciation of sections within. Admissions to a variety of wards enabled the women to meet a lot of peers. Made friendships and formed personal relationships.	<b>MDT:</b> Psychiatry and psychology help a lot and doing their best, helping by speaking about behaviours recommend treatment and medications to help. Talking about past horrific incidents with flash backs making the women angry and cry with nightmares.
4	<b>Vulnerability:</b> Vulnerable in relationships/bullied, mate crime, and refusal of professional interventions.	<b>Positive:</b> Participants could see how they worked with psychology and engage in DBT helps them along the way and prepare for discharge. Experiences were not awful all the time.	<b>Family contact:</b> Restrictions on spending time with family, limitations on family availability due to travel difficulties and physical ill health. Incremental visits to family home to help Mam get to know the woman in a	<b>Family:</b> Relationships and contact from family noted to be supportive.	<b>Male/female:</b> Specific male staff mentioned individually as being one of the best supports. There is noticeably a lack of male staff in the service, the women wonder why that is. Specific male staff have been loved/hated but made an

			close way.		impression on the women, naming them individually singling out; knowing their job role in the ward. Preferences made between one male staff and another.
5	<p><b>Comorbidities:</b> Labelling/diagnosis correlating with low mental health and episodes of being unwell. Co-existing conditions included paranoid schizophrenia, drug addictions, self-harm, attempting suicide. Effects of medication and female physical health problems included polycystic ovary syndrome</p> <p>shaded light blue indicates theme is linked to objective 2</p>	<p><b>Detainment/seclusion/Restraint:</b> Lengthy time is seclusion circular issue when behaviour deteriorated, no freedom and future at the mercy of a law court decision.</p>	<p><b>Choice:</b> Choose bedding but not type of mattress. Chose to give bank card to staff to help save up for expensive and luxury items.</p>	<p><b>Best place:</b> The ideal living situation would be in the community with staff 24/7 just like the ward except living alone.</p>	<p><b>Crime:</b> Crimes committed included arson and substance abuse. Arrest and detainment due to being poorly and unawareness of actions. The women were reluctant to have the contact with CJS, noted to avoid court appearances. The sentence time needs to be looked at, appeal of a section six months then yearly is lengthy. Consideration needs to be given to learning difficulties in relation to reading and accessing legal documents including dyslexia.</p>



6	<b>Sexuality:</b> Whilst living in the community spending time with gay people. Being in same sex relationships with other women who were patients on the same ward as well as having a boyfriend, being bi-sexual also history of being married and having a husband.	<b>Activities:</b> An extensive range of activities available to the women. Including work experience in the hospital.	<b>Friendships/peers:</b> Wards enabled friendships to be made but transitioning did not always facilitate the friendships to be maintained. Some of the women kept in touch by text and phone.	<b>Independence:</b> Length of time was given on admission to be five years, then discharged after 4 and a half. Questioning the deprivation of liberty on the basis of being vulnerable and no crime committed.	
7	<b>Multiple assessments:</b> Physical health assessments for epilepsy, medications, women's health assessments also discussing in detail the side effects of medications.	<b>Independence:</b> Going outside the hospital gives a sense of independence, some lived on a ward alone and others referred to transitioning for 18 months to own flat.		<b>Wider staff support:</b> Activity centre staff and members of MDT are supportive asking about progress and giving requests.	<b>Diagnosis:</b> mild learning disability, mental health conversion syndrome and paranoia were diagnoses that were relayed by the women. Comparisons made to the reasons for admission in that, not because of alcohol, more pointed towards wanting to end my life
8	<b>Treatment:</b> Engaging with treatment through attending DBT, leave discretionary at the mercy of the law court. The aim of engagement was for discharge back to community. Whilst needing time to come to terms with current situation.	<b>Family:</b> Mother admitted to same ward at same time triggered a move from low to medium secure.		<b>Advice:</b> The women gave advice for students who will be the future nurses in the service. Tell them	<b>Everyone is happy:</b> A notable settled status where the women are just getting on with 'it'. More time

				<p>what to expect and how to help patients go to a private place to talk let them talk about their problems a problem shared is a problem halved. Keep calm and keep a low voice give time out give prn and if it doesn't work only then pull alarms.</p>	<p>in the ward enables talking to new staff more.</p>
9	<p><b>Non-engagement:</b> Refusal of professional interventions, having the ability to abscond from secure wards.</p>				<p><b>Medication:</b> Previous prescription for anti-psychotic behaviour whilst in the community, now only paracetamol. The women have an understanding of medication, side effects and the reasons why they have been prescribed it.</p>
10	<p><b>Discharge planning:</b> Working towards leaving secure service by engaging with psychology and psychiatry to ultimately show the courts that treatment has been positive. Remaining substance free and showing the ability to make friends with the right kind of people.</p>				<p><b>Future/advice:</b> The women gave advice for staff in the form of treating them nice, and not being awful to them. Speak in an even tone and don't</p>

	The right placement is needed which is problematic to find.				shout, have some respect for the women. Little things like buying a squirt gun means a lot.
11	<b>Relationships:</b> Not a straightforward family composition, abused by a parent assaulted parent, adoption having boyfriend and girlfriend.				<b>Students:</b> The women are friendly and helpful to students, welcoming them into the ward and allowing them to do interventions and to go into their bedroom. <b>Orange shade relates to objective 4</b>
12	<b>Living a community life:</b> Now in employment, having a social life and attending further education.				<b>School/education:</b> School education was hindered because everything was done for the women.
<b>STAFF PRESENT AND CONTRIBUTED</b>	<b>Conversing/discussing</b> activities the P attends Staff asked would it be better mixed staff P said yes, some people find it easier to talk to males  <b>This area shaded grey indicates the data here relates to objective 1</b>	<b>Corroboration;</b> P asked staff member about ward names staff member corroborates moving from medium to low security	<b>Reminding:</b> Staff mentioned P has unescorted leave Staff mentioned P is due for imminent discharge	<b>Triangulation:</b> My named nurse you have studied her today Staff member clarified the input of advocate	<b>Specific learning difficulty:</b> Talking about dyslexia P saying she must be thick staff member gave reassurance and reminded P studying maths and English Gave confidence

**Table 20: Candidate themes from step 3 – the nurses**

	Q1	Q2	Q3
	How do you support women with an ID?	How prepared and trained do you feel to engage and support women with an ID?	How do you feel you might develop this approach both in the short and long term?
1	<p><b>Possession of staff and the women:</b> Referring to the women, staff and ward using a singular possessive pronoun as well as referring to the women as ours</p> <p><b>Green shade indicates theme linked to objective 3</b></p>	<p><b>Possession:</b> Participants refer to the staff in a possessive sense, gives three groups of staffing in terms of length in service. Long standing ten years plus, five years plus then one year plus. Length of service, being happy and staying in the job.</p>	<p><b>Future proofing</b> – improving services through reflexivity, national Standards, staff support and workforce planning, implementing new nurse associate training on the ward</p>
2	<p><b>Trauma:</b> Identifies that all the women have experienced trauma of some sort in their lives, this informs the way the nurses support the women piloting the implementation of TIC focusses on trauma and histories not just risk and diagnosis and will be implemented across male services</p>	<p><b>Learning on the job- in at the deep end:</b> Starting the job is described as in at the deep end, learning each day and university not fully preparing for the role as a RN in secure female services, its looking at evidence and research which is good but not for everyday clinical practice The requirement to involve HCAs in decisions, importance of reflection when things go wrong experiential learning with the women brings confidence biggest learning was working on the bank as a HCA no preceptorship in a training school you were handed the keys</p>	<p><b>National /professional recognition:</b> being multidisciplinary in nature And creating good networks with other staff and professions</p>
3	<p><b>Ability:</b> The women have varying ability thus varying needs, the women generally have mild or borderline ID with an IQ of 60 and above. Whilst high functioning their MH affects ability, often MH takes the</p>	<p><b>Further training:</b> In house training; TIC, Leadership, autism, mandatory, PD, DBT, PBS, Coaching, physical health, sexual abuse, St Andrews, suicide prevention and more is needed on female and families</p>	<p><b>Implementing /driving change:</b> improving services for women, utilising least restrictive service models, especially for females, and community based</p>

	forefront		
4	<p><b>Models of nursing intervention:</b> Implementing a new way of working by introducing Trauma Informed Care. This acknowledges the trauma suffered by the women, focussing on engagement and participation, structured throughout the day at key times. Acknowledging when the women are upset after speaking with family or upset at birthdays/significant dates. Care zoning is also implemented, the women decided on the colours. Colours are reviewed by HCA and RN gives responsibility to HCA and acknowledges their input in supporting the women on the shop floor. DBT and RODB are also some of the other main treatment foci.</p>	<p><b>Transient workforce:</b> You can tell when they are going to stay or leave, having to leave for experience and promotion and returning in that higher position, staff graded as long standing [10 yr+] and medium 3 yr+ and new to the ward months to 1 yr. a regular core group of bank staff who work into the wards it is difficult for new staff, transferred to the women's secure days later started there I was devastated</p>	<p><b>Improved staff support – evidence based:</b> Discuss emotional intelligence for staff dealing with patients as well as each other, especially recognising trauma but not using terms in a flippant matter. Showing the evidence base for why the women have a diagnosis and the staff may not, as well as being cognisant of the fact that one needs a good mix of personality types to work together</p>
5	<p><b>New ways of working for the nursing staff:</b> A new way of working gives the team a different perspective and a different way of supporting the women. Concentrating on key times in the day when the women are most likely to have decreased mood but also the opposite thereof and when the women are likely to be settled. RODB is suitable for people with Autism and some of the women are starting this method of treatment. Receiving a new admission is a new way of</p>	<p><b>The right person for the job:</b> You just know by attitude if they have the right care and compassion how they approach the role I can relate better to females because I am one, previously started in residential then moved into forensics now its anyone coming into work in the service, new starters work for one day then go sick and never come back Nobody saw it as a promotion it was a demotion you are caring for the women because of</p>	<p><b>Role modelling:</b> Important to have senior staff role model for qual/unqual staff to model their responses to patients. Also, positive role model for the women. Asking the staff and the women for feedback. Male staff are positive role models.</p>

	working for all the staff team as everyone is different.	their trauma the males are the perpetrators	
6	<b>Inter-professional working for engagement:</b> The collaborative nature of how the nurses work inter/multi professionally. Ensuring a widespread and vast range of activities is available to the women. Offered at the activity centre in the hospital site or in the ward.	<b>Friendly staff/saying the right thing:</b> Being happy having a smile it's the little things that make a massive difference being open we all have a mam and dad so do the women, not share some information with male patients but with the women its different	<b>Myth busting:</b> It appears there are a lot of myths and stigma in female forensic wards, this needs to change as the staff and service is changing and developing and it may be more about poor management of service than, issues with the women being dangerous. Issues between safety of staff and scaremongering must be balanced. Many positive aspects of Female forensic services.
7	<b>Engagement:</b> this theme refers to the activities and engagement of the women in treatment and activities. It also refers to how the women may not engage in these activities, comparing higher levels of engagement through TIC as opposed to restrictive practice.	<b>Discharge planning:</b> Previously there was movement between low/medium secure wards now its Transforming Care, aim is to discharge into the community some of the women in the wards for ten years + teams of staff desperately trying to find places	<b>Risk/person centredness:</b> difficult balance between risk to staff and the women, being patient centered Using humour to overcome pressure of risk/cope with complexities
8		<b>Saying and doing the right thing:</b> Talking about what to say and what not to say and how to do the right thing and creating the right atmosphere constantly re-thinking about things need to think about everything, keeping people motivated significant number of the women with personality disorder which means jealousy is a major issue where keeping people motivated	<b>Families/Being candid:</b> Having dialogue with the women about families, acknowledging the women are more sentimental than men about families, reassuring the women about their families, telling them how it is, arranging contact, gifts and visits, telling the women about [the nurses] own families
9		<b>Career trajectory:</b> Considered to be fortunate with secondment into	<b>Female/male:</b> Making comparisons between male and female secure

		nurse education old style nurse training school	service provision, comparing uncharacteristic behaviour of females do not present in males, crimes more serious in males, the women respond positively to female older staff, working is less stressful in male service and there are less incidents, it was a job in males but more personal with the women
10		<b>Female/male:</b> How rewarding it is working within female secure services very different to working with men not a lot of men want to work with females the male members of staff who do work in women's are good role models the women respond well to males good in relation to their trauma it is good for the women to see a man who can be positive role model, empathise with the women because of their circumstances, women hold a grudge and things linger the men deal with it then move on	<b>Discharge planning:</b> inter professional and collaborative working to plan for discharge, including the women in the plans and managing the women consideration of and incidents which may affect discharge
11		<b>Ways of working, interventions/models:</b> High staff ratios, intense management of behaviours female ward is draining adapted environment and removing items that have been weaponised burn out and trauma supervision for staff	<b>Trauma informed care /transforming care:</b> TIC as an intervention, the window of tolerance, inclusivity of the women, all wards, staff and families, enabling the women to see what they need to do for discharge as they may not have seen this before
12		<b>Staff support:</b> Being assaulted working in the service can be difficult for mental health and the importance of seeking support	<b>Relationships;</b> different types of relationships included patients from other wards, the hospital, different between male/female patients and maintaining family/children relationships, healthy

			relationships and consent to contraceptive advice
13		<b>Making a home:</b> Assessing prior to admission in a prison can be difficult and then compensating for that by creating a homely environment	<b>Idealism:</b> what the best service would look like, how to achieve it, what is needed the skills needed and qualifications of staff
14		<b>Parenting/families</b> Women are grieving for the children traumatic episodes of women trying to care for their baby at home unsupported and subsequent removal of the infant, long lost family searches to find and comparing with the men who accept someone is looking after their children and accept it. Women as sex workers and services failing them ended up in the ward for fighting, the progress coming from broken to healing	<b>Supporting students Nurses:</b> Encouraging student nurses to see perspectives of other professionals, experiencing other environments to see how a mentor has transferable skills and how working in one service gives a focussed perspective, showing the importance of many
15		<b>Decision making/MDTs:</b> Nurses as collaborators and the women in charge of their decisions opposite to that included the MDT making complex decisions about the women, the women responded positively to long standing staff someone new they wouldn't like it	<b>Future courses:</b> Development of future courses with clinical practice and uni, inclusion of gender studies and gender specific courses, module on female care content should include women's issues including menstruation and removal of children also PD course should include the histrionic one
16		<b>Attributes of the nurses:</b> Communication coping being strong able to listen to their trauma nothing phases and being laid back having empathy resilience, the nurses compared themselves with their husband as being a lot more challenging. Ability to verbally de-escalate as seen as important.	<b>Protective factors:</b> Safeguarding the women, listening to the women and acknowledging how vocal the women are



17		<b>Dealing with disclosures:</b> Disclosing abuse and having legal involvement providing the women with security and reassurance of protection from abuser, some of the women displayed behaviour to be secluded then use the time to disclose trauma, false accusations made by the women against male staff	<b>Physical health/Comorbidities:</b> incidence of other physical illness, the need to know about pharmacology and anti-psychotics
18		<b>Violence and aggression:</b> The nurses sustain injuries rationalising this by seeing it as a failure on their part in that they let it happen additionally, seeing the violence as the women lashing out because of their circumstances	<b>Women's issues:</b> Therapy to include women's issues on motivation and self-esteem, acknowledging how harder this is for women than men importance of dismissing important signs when apathy is depression
19		<b>Perceptions of other:</b> Male lecturer telling student nurses how he hated female secure and saw the women as aggressive and manipulative	<b>Instinctive characteristics – you just know:</b> Characteristics you don't get from the literature you get it, or you don't, its personal you feel more passionate about the women, working with the women changed me and I saw things differently
20			<b>Making a secure ward homely:</b> Recognising the need for the women to have a home acknowledging they have come from different backgrounds coming from home or prison may affect expectations, balancing risk with creativity to provide a homely environment, link incidents to special family times like Christmas, as this is the worst time for some of the women
21			<b>Violence/aggression:</b> Accessing medical attention following incidents difficult to access four to one ratio

			needed and soft cuffs required, the women see medical attention following an incident as total care and being looked after, manage the men with jovial approach and de-escalation quite a different approach is needed with the women they take everything personally a completely different approach is needed
22			<b>Families:</b> Reassuring the women about their family, organising and maintaining contact
23			<b>Happy people:</b> Humour as an integral aspect to the role of the nurse in keeping staff happy as well as making the women laugh helping everyone see things as not all bad
24			<b>Trauma:</b> Nearly all the women have experienced trauma in some form, losing children or victims of abuse. There has been a shift in society through education, accessing information and social media in dealing with domestic violence and abuse, the women's service has also developed. Intelligent women have been unable to protect themselves or articulate their abuse, how can we expect a woman with ID to do this. Specific episodes told of the women and response to intervention as in PTSD [not mentioned specifically]
25			<b>Protective Factors:</b> Relying on how vocal the women were on speaking up was if something was wrong
26			<b>Diagnosis:</b> An important issue in ID, how

			a diagnosis of having an ID changes everything, also how re assessment may reveal the woman as not having an ID
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END OF THESIS